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ORIGINAL RESEARCH

Accuracy of Death Certificates in Attributing Mortality to Alzheimer's Disease and Other Dementias in Japanese Psychiatric Hospitals

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Aim: Dementia, including Alzheimer's disease (AD), is a leading cause of mortality in Europe and the United States. Interestingly, while Japan is recognized for its high life expectancy, dementia-related diseases account for a comparatively lower proportion of recorded deaths. This study aimed to investigate the actual mortality attributed to clinically diagnosed AD in Japan, particularly in psychiatric hospital settings.

Methods: Total 653 cases Death certificates and medical records from psychiatric hospitals in Japan were analyzed to investigate the actual death rate associated with dementia diseases.

Results: In total, 134 of the 653 cases (20.5%) were determined to have AD as the direct cause of death, a significant increase from the 34 cases initially identified from death certificates alone (P<0.01). And more, after reviewing the death certificates and medical records of 653 patients, 203 (134 with AD and 69 with other dementias) were identified as having dementia as the direct cause of death, representing 31.1% of all deaths. This rate was significantly higher than the rate identified before the medical record review (P<0.01). Dementia diagnoses were frequently omitted from death certificates, with complications often recorded as the primary cause of death. This suggests that the true incidence of dementia-related mortality in Japan may be approximately four times higher than reported.

Conclusion: We found that the true incidence of dementia-related mortality in Japan may be higher than reported. These findings underscore the critical need to increase awareness about dementia as a cause of death and to educate the public and healthcare professionals on accurately documenting it on death certificates.

Keywords: Alzheimer's disease, cause of death, death certificate, dementia diseases, Japan

Introduction

The prevalence of dementia is increasing worldwide, with projections estimating that the number of individuals affected will reach 150 million by 2050.[1,2] Alzheimer's disease (AD) and other major forms of dementia are progressive neurodegenerative disorders that affect the entire body, ultimately leading to death from complications and associated conditions.[3,4] Patients with Vascular dementia (VD) often succumb to cerebrovascular disease or myocardial infarction; however, VD itself can result in pathologies such as aspiration pneumonia, which can also be fatal.[5]

As awareness grows regarding dementia as a terminal condition, it has become a focus of palliative care in many countries.[6,7] Consequently, AD and other dementias rank among the leading causes of death in European countries and the United States (US). Notably, AD is the most common form of dementia, accounting for approximately 60% of all cases, with a reported death rate of 13% in France, 12% in the United Kingdom, and 7% in the US.[8]

Although the prevalence of dementia increases with age, Japan, despite having one of the longest life expectancies globally, reports a lower ranking of dementia as a cause of death compared to that in other countries. The reported mortality rate for AD and other dementias in Japan is 1.6% for both, significantly lower than rates observed in Western countries.[9] Conversely, "senility" ranked as the third leading cause of death in Japan's 2018 mortality statistics,

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accounting for 8% of deaths. This discrepancy has sparked debate over whether deaths caused by dementia are being inaccurately documented as senility on death certificates.[10,11]

The idea that dementia should be recognized as a cause of death was proposed by Molsa et al[5] in 1986 and is now well established in many countries. However, even in the US, where dementia ranks higher as a cause of death than in Japan, the underreporting of dementia-related mortality remains a contentious issue.[12] Research has estimated that the actual death rate due to dementia in the US is approximately 14%, whereas only approximately 5% is officially recorded.[13] Japanese death statistics are compiled based on death certificates issued by physicians. The first author, a psychiatrist with extensive experience in internal medicine, observed that in psychiatric hospitals, where many patients with dementia are admitted, the cause of death listed on death certificates was often recorded as another condition, even when the patient had died of dementia. Although the proportion of deaths occurring in hospitals in Japan has been gradually decreasing, it still accounts for nearly 70% of all deaths. According to a 2020 survey by the Ministry of Health, Labour and Welfare (MHLW), a total of 75,900 individuals with dementia were hospitalized in Japan, including 50,600 with AD and 25,300 with other dementias. Of these, 39,200 patients with AD and 18,800 with other dementias were admitted to psychiatric hospitals, resulting in a total of 58,000 patients with dementia hospitalized in such facilities.[14] According to statistics from the MHLW, 76% (58,000) of all hospitalized Japanese patients with dementia are admitted to psychiatric hospitals. Japan has approximately 1.58 million hospital beds, of which approximately 20%, or 323,000 beds, are designated for psychiatric care. Of these, 244,000 beds are in psychiatric hospitals, and 79,000 are in general hospitals.[15] The majority of inpatient psychiatric care is provided in psychiatric hospitals. In recent years, there has been an increasing trend of patients with dementia being admitted to psychiatric hospitals and remaining there until death.[16,17]

We hypothesized that the low proportion of deaths attributed to dementia in Japanese mortality statistics may be due to the omission of AD and other dementias in the direct cause of death section on death certificates. To explore this, we aimed to investigate whether dementia was accurately recorded as the main diagnosis or direct cause of death on death certificates, focusing on psychiatric hospitals with a high number of inpatients with dementia. This analysis utilized both death certificates and medical records.

Methods

Participants

We examined the death certificates of patients who died in 11 psychiatric hospitals in the northern Kanto region of Japan between fiscal years (FY) 2010 and 2020. During this period, 942 deaths were recorded, with death certificates available for all cases and medical records accessible for 653 cases. Therefore, the 653 cases with both death certificates and medical records were selected for the present study (Figure 1).

All data used in this study were anonymized during the collection process to ensure individuals' confidentiality and informed consent was obtained from participants in the form of opt-out on the website. The study was approved by the Ethical Review Committee of Jichi Medical University (approval number: 23–139). The study protocol adhered to the Declaration of Helsinki guidelines.

Survey Items

The investigation of death certificates and medical records was conducted by Sato, a Board Certified Member of the Japanese Society of Internal Medicine. In cases where uncertainties arose during the review of medical records, particularly in determining the direct cause of death, the final determination was made in consultation with Shioda, who had worked as a general physician for many years.

From the total of 653 death certificates (male: 393; female: 260), we extracted the following information: age at death, sex, column I of the death certificate (Disease or condition directly leading to death), and column II of the death certificate (Other significant conditions contributing to death but not related to the disease or condition causing it). The direct cause of death was defined as the disease listed at the bottom of column I, in accordance with the methods prescribed by the World Health Organization (WHO) and the MHLW for identifying causes of death. The names of the

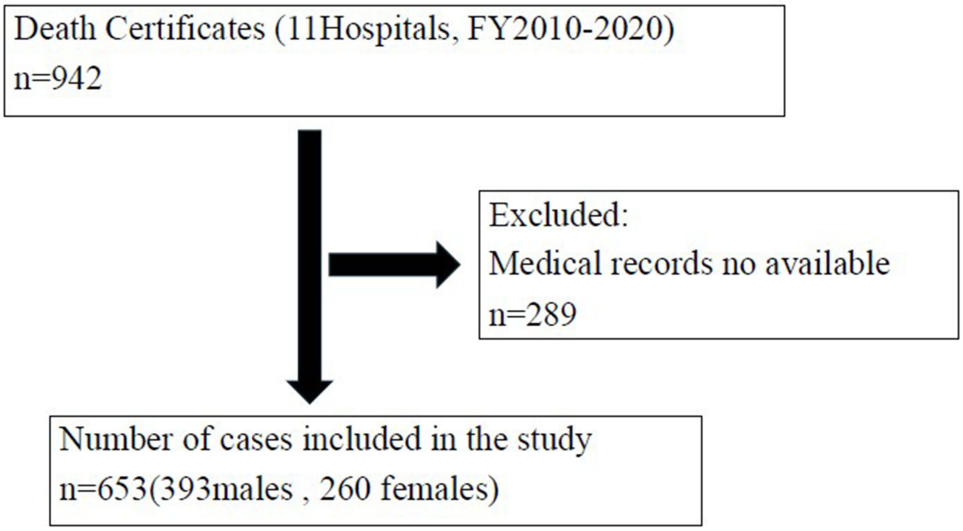

Figure 1 Consort flow diagram of study patients.

direct causes of death were classified using the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10), which is the standard classification system used in official death statistics in Japan.

We analyzed 653 medical records (male: 393; female: 260) of patients for whom records were available, focusing on the disease that led to admission, the presence of AD as a comorbidity, and the categorization of dementia as a cause of hospital admission (AD or other dementias). Additionally, we examined whether dementia was accurately documented in column I of the death certificate when AD or any other dementia was identified as the cause of death. The medical records were further reviewed to determine whether dementia had progressed to become a direct cause of death. In this study, death due to dementia was defined using two criteria:[1] the patient's condition prior to death met the National Hospice and Palliative Care Organization (NHPCO) definition of hospice care induction criteria (Table 1); and[2] the patient died from a condition attributable to dementia, such as pneumonia, asphyxia resulting from impaired swallowing, urinary tract infections and kidney failure due to dysuria, or infections related to pressure ulcers and other recurring conditions. Cases in which patients with dementia died from apparent malignant diseases, heart diseases, or cerebrovascular diseases were excluded.

Analysis

We categorized the mental disorders causing hospitalization into the following groups: AD (F00), other dementias (F0 excluding F00), mood disorder spectrum (F3), schizophrenia disorder spectrum (F4), and other mental disorders. The age at death was compared across these categories.

Based on the death certificates, we classified the direct causes of death for the 653 cases using the ICD-10 codes. The number of deaths for men, women, and the overall death rates were identified by ICD codes.

The medical records of 148 patients hospitalized for AD were reviewed to determine the appropriate direct cause of death. For each ICD code, we calculated the difference between the number of deaths recorded on the death certificate and the number of deaths corrected based on the medical record review.

Table 1 Hospice Criteria for Dementia

1	Dementia of sufficient severity (the patient has passed Stage 7-C of the Functional Assessment Staging (FAST) scale.)
2	The first occurrence of medical complications: Medical complications herald significant downturns in most demented patients. Those most often seen include aspiration pneumonia, upper urinary tract infection often including sepsis, worsening multiple stage 3–4 decubiti, fever recurrent after a course of antibiotics or greater than ten percent weight loss over six months.

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The medical records of 124 patients hospitalized for other dementias were reviewed to determine the appropriate direct cause of death. For each ICD code, the difference between the number of deaths recorded on the death certificate and the number of deaths corrected through medical record review was calculated.

The medical records of 13 patients with comorbid AD who were admitted for other mental disorders were reviewed to determine the appropriate direct cause of death and the mental disorder leading to hospitalization. Discrepancies between the number of deaths recorded on death certificates and the corrected number of deaths based on medical record investigations were identified.

We examined whether there were differences in the number of deaths attributed to AD between death certificates and the corrected number of deaths. The proportions of AD deaths, as recorded on death certificates and as determined by medical record review, were compared overall and by sex. Ratios were analyzed using the chi-squared (χ^2) test. Additionally, the χ^2 test was used to determine whether there were significant differences in AD mortality by sex.

We investigated whether there were differences in the number of deaths attributed to all dementias between death certificates and the corrected number of deaths. The proportion of dementia-related deaths, as recorded on death certificates and as determined by medical record review, were compared overall and by sex. Ratios were analyzed using the χ^2 test. Additionally, the χ^2 test was used to assess whether there were significant differences in dementia-related mortality by sex.

A P-value of <0.05 was considered statistically significant. All statistical analyses were conducted using IBM SPSS statistics for Windows, version 26.

Results

A total of 942 death certificates were identified for patients who died between FY 2010 and FY 2020 in 11 psychiatric hospitals. Of these, 393 were male, and 260 were female, resulting in a total of 653 patients for which both death certificates and medical records were verified (Figure 1).

Mental Disorders Causing Hospitalization and Associated Age of Death

We categorized mental disorders causing hospitalization into AD (F00), other dementias (F0 excluding F00), mood disorder spectrum (F3), schizophrenia disorder spectrum (F4), and other psychiatric disorders. The age at death was analyzed for each disorder.

The most common mental disorder was schizophrenia (293 cases), followed by AD (148 cases) and other dementias (124 cases) (Table 2). The average age at death for patients with AD and other dementias was over 80 years. In contrast, the average age at death for patients with other conditions was approximately 70 years (Table 2).

Causes of Death Based on Death Certificates (by ICD Code)

The results derived from death certificates showed that the leading cause of death was classified under ICD-10 code J, with pneumonia and aspiration pneumonia accounting for 40.3% (263 cases) of all deaths. The second most common

Table 2 Mental Disorders Causing Hospitalization and Associated Age of Death

	Male (Cases)	Age at Death y.o±SD	Female (Cases)	Age at Death	Total (Cases)	Age at Death
AD	86	83.47±6.66	62	84.5±7.26	148	83.93±6.91
Other Dementias	78	80.37±6.96	46	81.98±9.37	124	80.97±7.94
Mood Disorders	19	68.26±7.06	12	77.5±11.56	31	71.84±9.99
Schizophrenia	175	69.09±10.22	118	72.06±10.66	293	70.27±10.48
Others	35	65.74±14.68	22	69.77±16.43	57	67.30±15.36
Total	393	74.12±11.51	260	78.55±11.83	653	75.21±11.21

cause was ICD-10 code I, representing heart failure and other diseases of the circulatory system, which accounted for 17.6% (115 cases) of deaths. Neoplasms, categorized under ICD-10 code C, were the third most common cause, comprising 12.6% (82 cases) of total deaths. AD accounted for 5.2% (34 cases) of total deaths, while other dementias combined accounted for 6.9% (45 cases).

Furthermore, 6.6% (43 cases) were classified as others (code R), including 5.4% (35 cases) attributed to senility (Table 3).

Changes in Direct Cause of Death Before and After Medical Record Confirmation for Patients Admitted with AD

We examined whether patients admitted with AD were accurately reported as having died from AD. Among 148 cases of patients hospitalized with AD, only 34 death certificates listed AD as the direct cause of death. However, after reviewing the medical records and identifying cases that met the definition of death due to dementia, it was determined that AD should have been listed as the direct cause of death in 116 of the 148 cases.

A review of medical records where AD was already listed as the direct cause of death on the death certificate confirmed that all these cases met the criteria for dementia-related death, supporting the accuracy of AD as the direct cause of death. For other cases, the direct cause of death was revised as follows: in 43 out of 47 cases of pneumonia and all nine cases of

Table 3 Causes of Death Based on Death Certificates (by ICD Code)

ICD Code	Male	%	Female	%	Total	%
A00-B99 Infectious and Parasitic Diseases	6	1.53%	2	0.77%	8	1.23%
C00-D48 Neoplasms	47	11.96%	35	13.46%	82	12.56%
D50-D89 Diseases of the Blood and Blood-Forming Organs and Certain Disorders Involving the Immune Mechanism	8	2.04%	3	1.15%	11	1.68%
E00-E90 Endocrine, Nutritional and Metabolic Diseases Malnutrition N17-19	1 (1)	0.25% (0.25%)	3 (3)	1.15% (1.15%)	4 (4)	0.61% (0.61%)
F00-F99 Mental and Behavioural Disorders (AD) (Dementia; excluding AD)	25 (20) (5)	6.36% (5.09%) (1.27%)	20 (14) (6)	7.69% (5.38%) (2.31%)	45 (34) (11)	6.89% (5.21%) (1.68%)
G00-G99 Diseases of the Nervous System	2	0.51%	4	1.54%	6	0.92%
I00-I99 Diseases of the Circulatory System (Heart Failure J50)	59 (27)	15.01% (6.87%)	56 (32)	21.54% (12.31%)	115 (59)	17.61% (9.04%)
J00-J99 Diseases of the Respiratory System (Pneumonia J18) (Aspiration Pneumonia J69)	182 (147) (28)	46.31% (37.40%) (7.12%)	81 (71) (9)	31.15% (27.31%) (3.46%)	263 (218) (37)	40.28% (33.38%) (5.67%)
K00-K93 Diseases of the Digestive System	15	3.82%	18	6.92%	33	5.05%
L00-L99 Diseases of the Skin and Subcutaneous Tissue	1	0.25%	1	0.38%	2	0.31%
N00-N99 Diseases of the Genitourinary System (Urinary Tract Infection N39) (Renal Failure N40-46)	8 (2) (5)	2.04% (0.51%) (1.27%)	13 (4) (8)	5.00% (1.54%) (3.08%)	21 (6) (13)	3.22% (0.92%) (1.99%)
R00-R99 Symptoms, Signs and Abnormal Clinical and Laboratory Findings, Not Elsewhere Classified (Senility R54)	26 (19)	6.62% (4.83%)	17 (16)	6.54% (6.15%)	43 (35)	6.58% (5.36%)
V01-Y98 External Causes of Morbidity and Mortality	13	3.31%	7	2.69%	20	3.06%
Total	393		260		653	100.00%

Table 4 Changes in Direct Cause of Death Before and After Medical Record Confirmation for Patients Admitted with AD

ICD Code	Male		Female		Total		Change
	Before	After	Before	After	Before	After	
A00-B99 Infectious and Parasitic Diseases	1	0	1	1	2	1	−1
C00-D48 Neoplasms	5	5	3	3	8	8	0
D50-D89 Diseases of the Blood and Blood-Forming Organs and Certain Disorders Involving the Immune Mechanism	2	2			2	2	0
E00-E90 Endocrine, Nutritional and Metabolic Diseases (Malnutrition N17-19)							
F00-F99 Mental and Behavioural Disorders (AD) (Dementia; excluding AD)	21 (20) (1)	67 (67) (0)	14 (14)	49 (49)	35 (34) (1)	116 (116) (0)	+81 (+82) (−1)
G00-G99 Diseases of the Nervous System							
I00-I99 Diseases of the Circulatory System (Heart Failure J50)	9 (6)	5 (2)	6 (3)	4 (1)	15 (9)	9 (3)	−6 (−6)
J00-J99 Diseases of the Respiratory System (Pneumonia J18) (Aspiration Pneumonia J69)	35 (27) (6)	3 (2) (0)	23 (20) (3)	2 (2) (0)	58 (47) (9)	5 (4) (0)	−53 (−43) (−9)
K00-K93 Diseases of the Digestive System	4	4	3	3	7	7	0
L00-L99 Diseases of the Skin and Subcutaneous Tissue			1	0	1	0	−1
N00-N99 Diseases of the Genitourinary System (Urinary Tract Infection N39) (Renal Failure N40-46)	2 (2)	0 (0)	4 (3) (1)	0 (0) (0)	6 (3) (3)	0 (0) (0)	−6 (−3) (−3)
R00-R99 Symptoms, Signs and Abnormal Clinical and Laboratory Findings, Not Elsewhere Classified (Senility R54)	6 (6)	0 (0)	6 (5)	0 (0)	12 (11)	0 (0)	−12 (−11)
V01-Y98 External Causes of Morbidity and Mortality	1	0	1	0	2	0	−2
Total	86	86	62	62	148	148	0

aspiration pneumonia, the direct cause of death was corrected to AD; all 11 cases classified as senility were corrected to AD; 6 out of 9 cases of heart failure were corrected to AD; all 3 cases of renal failure and 3 of urinary tract infections were corrected to AD; one case of infectious and parasitic diseases and one case of diseases of the skin and subcutaneous tissue were corrected to AD; 2 cases classified under external causes of morbidity and mortality were corrected to AD; one case initially labeled as dementia was corrected to AD, as the diagnosis in the medical record specified AD (Table 4).

Changes in Cause of Death Before and After Medical Record Confirmation for Patients Admitted with Dementias Other Than AD

The study included 124 patients admitted with dementias other than AD (other dementias). Among these, the primary cause of death listed on the death certificate was dementia in only 10 cases, accounting for less than one-tenth of the total. After reviewing the medical records and identifying cases that met the definition of death due to dementia, it was determined that dementia should have been listed as the direct cause of death in an additional 64 of the 124 cases.

A review of medical records where dementia was already listed as the direct cause of death on the death certificate confirmed that all these cases met the criteria for dementia-related death, supporting the accuracy of dementia as the direct cause of death.

Table 5 Changes in Cause of Death Before and After Medical Record Confirmation for Patients Admitted with Dementias Other Than AD

ICD Code	Male		Female		Total		Change
	Before	After	Before	After	Before	After	
A00-B99 Infectious and Parasitic Diseases	2	0			2	0	−2
C00-D48 Neoplasms	3	3	3	3	6	6	0
D50-D89 Diseases of the Blood and Blood-Forming Organs and Certain Disorders Involving the Immune Mechanism	1	1	1	1	2	2	0
E00-E90 Endocrine, Nutritional and Metabolic Diseases (Malnutrition N17-19)							
F00-F99 Mental and Behavioural Disorders (Alzheimer's Disease) (Dementia: excluding AD)	4 (0) (4)	48 (4) (44)	6 (0) (6)	26 (1) (25)	10 (0) (10)	74 (5) (69)	+64 (+5) (+59)
G00-G99 Diseases of the Nervous System	0	0	1	1	1	1	0
I00-I99 Diseases of the Circulatory System (Heart Failure J50)	17 (9)	12 (4)	10 (6)	7 (3)	27 (15)	19 (7)	−8 (−8)
J00-J99 Diseases of the Respiratory System (Pneumonia J18) (Aspiration Pneumonia J69)	39 (29) (10)	11 (11) (0)	18 (17) (1)	4 (4) (0)	57 (46) (11)	15 (15) (0)	−42 (−31) (−11)
K00-K93 Diseases of the Digestive System	0	0	4	4	4	4	0
L00-L99 Diseases of the Skin and Subcutaneous Tissue							
N00-N99 Diseases of the Genitourinary System (Urinary Tract Infection N39) (Renal Failure N40-46)	2 (0) (1)	2 (0) (1)	1 (1) (0)	0 (0) (0)	3 (1) (1)	2 0 (1)	−1 (−1) (0)
R00-R99 Symptoms, Signs and Abnormal Clinical and Laboratory Findings, Not Elsewhere Classified (Senility R54)	8 (7)	0 (0)	2 (2)	0 (0)	10 (9)	0 (0)	−10 (−9)
V01-Y98 External Causes of Morbidity and Mortality	2	1	0	0	2	1	−1
Total	78	78	46	46	124	124	0

For other cases, the direct cause of death was revised as follows: in 31 out of 46 cases of pneumonia and all 11 cases of aspiration pneumonia, the direct cause of death was corrected to dementia; all 9 cases initially classified as senility were corrected to dementia; 8 of 15 cases of heart failure were corrected to dementia; one case categorized under ICD-10 code R (multi-organ failure) was corrected to dementia; a case of urinary tract infections was corrected to dementia; 2 cases of infectious and parasitic diseases were corrected to dementia; one case classified under external causes of morbidity and mortality was corrected to dementia; 5 cases diagnosed with other dementias at the time of admission were reclassified as AD, and their cause of death was corrected to AD (Table 5).

Causes of Death in Cases of Comorbid AD and Hospitalization for Other Mental Disorders

The same investigations were conducted for cases where the primary reason for hospitalization was a mental disorder other than AD or other dementias but where AD was present as a complication. Among these, 11 patients were admitted with schizophrenia and 2 with bipolar disorder, both complicated by AD. For the 11 patients with schizophrenia, the direct causes of

death listed on death certificates were as follows: pneumonia (five cases), aspiration pneumonia (two cases), senility (two cases), and heart failure (two cases). After a medical record review, all 11 cases were corrected to AD as the direct cause of death. For the two patients with bipolar disorder, the direct causes of death listed on death certificates were pneumonia and aspiration pneumonia. Both cases were also corrected to AD as the direct cause of death.

Appropriate AD Death Rate in Psychiatric Hospital Inpatients

The results showed that AD was the direct cause of death in 116 patients hospitalized with AD, 5 patients hospitalized with other dementias, and 13 patients hospitalized with other mental disorders. The proportion of AD-related deaths reported on death certificates and the corrected number of AD-related deaths after medical record confirmation were compared overall and by sex. In total, 134 of the 653 cases (20.5%) were determined to have AD as the direct cause of death, a significant increase from the 34 cases initially identified from death certificates alone (P<0.01). Similarly, by sex: among male patients, 20 of 393 cases (5.1%) were recorded as AD-related deaths before medical record confirmation, while 78 cases (19.8%) were identified after confirmation (P<0.01). Among female patients, 14 of 260 cases (5.4%) were recorded as AD-related deaths before medical record confirmation, while 56 cases (21.5%) were identified after confirmation, also showing a significant difference (P<0.01). The mortality rate due to AD after medical record review was significantly higher in men than in women (P=0.035) (Table 6).

Appropriate Dementia-Related Death Rates in Psychiatric Hospital Inpatients

After reviewing the medical records of 653 patients, 203 (134 with AD and 69 with other dementias) were identified as having dementia as the direct cause of death, representing 31.1% of all deaths. This rate was significantly higher than the rate identified before the medical record review (P<0.01).

When examining dementia-related deaths by sex: among males, 122 out of 393 patients (31%) were determined to have dementia as the direct cause of death, a significant increase compared to the rate before the medical record review (P<0.01). Among females, 81 out of 260 (31.1%) patients were determined to have dementia as the direct cause of death, also showing a significant increase (P<0.01) (Table 7). The mortality rate due to all dementias after the medical record review showed no significant difference between males and females (P=0.975).

Table 6 Difference in the Number of Patients Considered to Have AD as the Cause of Death

	Deaths Due to AD Before Medical Record Review	Non-AD Cases Before Medical Record Review	Deaths Due to AD After Medical Record Review	Non-AD Cases After Medical Record Review	P value
Total	34	619	134	519	P<0.01
Male	20	373	78	315	P<0.01
Female	14	246	56	204	P<0.01

	Deaths Due to AD after Medical Record Review	Non-AD Cases after Medical Record Review	P value
Male	78	315	P=0.04
Female	56	204	

Table 7 Difference in the Number of Patients Considered to Have Dementia (Including AD) as the Cause of Death

	Dementia Cases Before Medical Record Review	Non-Dementia Cases Before Medical Record Review	Dementia Cases After Medical Record Review	Non-Dementia Cases After Medical Record Review	P value
Total	45	608	203	450	P<0.01
Male	25	368	122	271	P<0.01
Female	20	240	81	179	P<0.01

(*Continued*)

Table 7 (Continued).

	Dementia Cases after Medical Record Review	Non-Dementia Cases after Medical Record Review	P value
Male	122	271	P=0.98
Female	81	179	

Discussion

A survey of the causes of death based on death certificates, categorized by ICD code, revealed that respiratory diseases accounted for approximately 40% of all deaths, followed by cardiovascular diseases at 17.6%, with half of these cases listed as heart failure.

The underlying cause of death, which forms the foundation for mortality statistics, is determined according to WHO guidelines. Under these guidelines, the illness or injury listed at the bottom of column I on the death certificate is considered the direct cause of death. However, the WHO specifies that terminal conditions, such as heart failure or respiratory failure, are not appropriate as direct causes of death.[8]

Additionally, 6.6% of deaths were categorized under the ICD-10 R code, which were found to be inappropriate as direct causes of death, with senility alone accounting for 5.4% of these cases. This indicates that inappropriate causes, such as heart failure and senility, were frequently listed as the direct cause of death. These findings highlight that death certificates in Japanese psychiatric hospitals are often not completed in accordance with proper standards.

Patients admitted with AD or other dementias accounted for 42% of the total, but only approximately 7% of the total deaths. Among patients admitted with AD, only 25% had AD listed as the cause of death on their death certificate. Respiratory diseases were the most common cause of death, accounting for approximately 40%, with most cases involving pneumonia, including aspiration pneumonia. This finding aligns with those of previous studies.[18–21] However, in 91% of the cases where pneumonia and aspiration pneumonia were listed as the cause of death, it was believed that the progression of AD led to impaired swallowing and other functional declines, ultimately resulting in pneumonia.

Clinically, determining whether complications or the underlying disease is the true cause of death is often challenging. This determination also depends on the country's rules for selecting the underlying cause of death. For example, in Canada and the United Kingdom[22,23] the rule is that if a patient with dementia dies of aspiration pneumonia, dementia is considered the cause of death. While similar rules have been adopted in Japan, they are not widely recognized in clinical practice.

This discrepancy is also evident in the US, where dementia is reported on death certificates for only a quarter of dementia-related deaths despite being a leading cause of death. A US cohort study reported a significant increase in mortality associated with the incidence and progression of AD, suggesting that AD contributes to more deaths than are officially recorded.[24,25]

In contrast, countries such as France and Italy report higher rates of dementia as the underlying cause of death. In Italy, dementia is listed in approximately 12–19% of cases, while in France, it is listed in approximately 26–33% of cases. These differences highlight how the tendency to underreport dementia as a cause of death may vary by country.[26]

In this study, approximately 7% of patients hospitalized for AD had "senility" listed as the cause of death. Unlike in other countries, senility is a leading cause of death as per Japan's mortality statistics. Originally, senility was defined as "symptoms, signs, and abnormal clinical or detection findings that are not classified elsewhere", making it a condition with an unclear diagnosis. In Japan, it is generally considered acceptable to record "senility" as the cause of death on death certificates, particularly in settings such as nursing homes and home-based palliative care.[27]

In contrast, in Europe and the United States, listing only terms such as "senility" or "natural causes" is typically regarded as insufficient for determining the underlying cause of death. This practice may also complicate postmortem investigations or insurance procedures; hence, physicians are strongly encouraged to specify a definitive medical diagnosis.[28]

In Japan, the rate of deaths attributed to senility has quadrupled, rising from 2.6% in 2000 to 10.3% in 2020. In contrast, the rate is only 0.8% in France and 0.2% in the US, highlighting a significant international discrepancy.[29] In many cases, listing senility as the primary cause of death is inappropriate, particularly when dementia is the underlying condition that leads to a gradual decline and eventual death. Nevertheless, in this study, there were cases where only senility was recorded as the primary cause of death.

Hayashi et al reported that 90% of death certificates listing senility as the cause of death did not mention any other causes, and this percentage has been increasing over time.[29] This raises an important question: was senility truly the sole cause of death, or were there underlying diseases that went unlisted? Based on our investigation, it is likely the latter, indicating a need for a better understanding of dementia, clearer definitions of senility, and greater public awareness about the proper completion of death certificates.

Additionally, the results of the medical record survey revealed six cases where heart failure was described as a terminal condition without detailed examination. The underlying cause of death, which serves as the basis for mortality statistics, is determined by the guidelines set by the WHO. According to these rules, if the condition listed in the bottom line of column I is likely to have caused all the other conditions listed above, it is considered the underlying cause of death. However, if an inappropriate condition is listed in column II as the cause of death, it may be inaccurately classified as such. Furthermore, the WHO guidelines advise against listing terminal conditions, such as cardiac failure or respiratory failure, as the cause of death.

In this study, 124 patients with non-AD dementia were found to have psychiatric disorders that led to their hospitalization. Among the patients whose death certificates listed pneumonia and aspiration pneumonia as the cause of death, 74% may have developed pneumonia and aspiration pneumonia due to the deterioration of swallowing and other functions caused by the progression of dementia. Additionally, as seen in AD cases, there were nine instances where only senility was listed as the cause of death on the death certificate. Many cases also featured a diagnosis of dementia without further classification. In such instances, AD was often considered the underlying cause of death. These findings suggest that a significant number of cases may have had AD as the actual cause of death.

The results of the medical record survey indicated that in cases where AD was diagnosed alongside other psychiatric disorders, the cause of death was frequently misattributed, with some instances where it should have been recognized as resulting from AD. Notably, a significant number of patients with schizophrenia were identified with complications related to AD.

The risk of developing dementia among patients with ataxia is reported to be approximately twice as high as that in the general population.[30] Specifically, it is hypothesized that patients with schizophrenia who develop AD may experience heightened susceptibility to schizophrenia-like symptoms due to the progressive decline in cognitive function.[31]

In diagnosing dementia, cognitive dysfunction observed in patients with schizophrenia during the early stages of their illness can complicate the timely diagnosis of dementia. This delay can hinder accurate estimation of the co-occurrence rates of schizophrenia and AD.[32] Comprehensive patient interviews and detailed examination findings are essential for differentiating schizophrenia from dementia. However, distinguishing schizophrenia from dementia based solely on clinical symptoms remains challenging.[33,34] This diagnostic difficulty may lead to underdiagnosis or misdiagnosis of both conditions, as the perceived benefit of differentiating between them might be minimal.

There was a significant increase in deaths attributed to AD across both sexes before and after the medical record survey. This rise can largely be attributed to complications of AD, such as pneumonia, being documented as the immediate cause of death, while AD, as the underlying condition, was often omitted from the records.

Overall, in this study, the appropriate cause of death was identified by analyzing the diseases and medical conditions listed in patients' medical records and comparing them to the information documented on death certificates. This analysis revealed a significant increase in the reported mortality rate of AD and overall dementia. The findings suggest that while physicians often diagnose AD and dementia, there is insufficient recognition of dementia as a direct cause of death, leading to incomplete or inaccurate death certificates. Given that Japan's death statistics are based on these certificates, the actual number of dementia-related deaths in Japan is likely substantially higher than that officially reported.

Prior to the survey, 34 out of 653 deaths (5.2%) were attributed to AD, whereas post-survey, this number increased to 134 out of 653 (20.5%), representing nearly a fourfold rise. These findings imply that while the official number of deaths due to AD in Japan is approximately 25,000, the actual figure could be closer to 100,000. Similarly, deaths attributed to total dementia increased from 45 out of 653 (6.9%) before the survey to 203 out of 653 (31.1%) after the survey, approximately 4.5 times higher. These results suggest that the actual number of dementia-related deaths in Japan might be approximately 220,000, surpassing the approximately 190,000 deaths reported due to senility and potentially making dementia the third leading cause of death in the country.

These findings indicate that the number of deaths due to dementia, including AD, is significantly underreported on death certificates. As approximately 30% of the deaths in psychiatric hospitals analyzed in this study were attributed to dementia, it is imperative for medical personnel involved in psychiatric care to be well-informed about dementia, including AD. Furthermore, death certificates serve as foundational data for death statistics and are critical for national healthcare administration and policy decision-making. Therefore, even psychiatrists must possess adequate knowledge on how to accurately complete death certificates.

Additionally, in this study, heart failure was often not diagnosed following a thorough examination immediately prior to death, and some death certificates listed heart failure as a terminal condition for convenience. Villar et al reported that 56.8% of death certificates listed respiratory or cardiac arrest as the direct cause of death prior to educational interventions, whereas none listed these causes following such education.[35] This emphasizes the importance of proper training on accurate death certificate entries in Japan.

This study has some limitations. The result lacks broader applicability. It was conducted exclusively in the northern Kanto region of Japan, which may limit the applicability of its findings to other regions, as the practices for completing death certificates could vary geographically. Additionally, the study focused exclusively on psychiatric diseases, without including a death certificate survey in general hospitals or home care settings. Therefore, generalizing these findings to estimate the national mortality rate of dementia, including AD, across Japan may not be appropriate. Furthermore, It has been suggested that individuals with mental disorders receive less frequent medical evaluations.[36] Since the patients in this study were also hospitalized in psychiatric facilities, it is possible that serious conditions such as cancer and myocardial infarction were insufficiently investigated. Consequently, the potential for an elevated mortality rate for dementia, including Alzheimer's disease, in the medical record survey cannot be ruled out.

Although not relevant to the present study, we found that patients hospitalized with schizophrenia spectrum disorders, mood disorder spectrum disorders, and other mental disorders had shorter life expectancies than did those with AD or other dementias. Patients with schizophrenia have reduced life expectancies. Kiviniemi et al reported that patients with schizophrenia have a 4.45-fold higher risk of death than that in the general population,[37] and Owens et al noted that these patients have a life expectancy approximately 20% shorter than that of the general population.[38] In the present study, the age at death for patients with schizophrenia was approximately 10 years younger than for those with dementia.

In recent years, individuals with various mental disorders reportedly have significantly shorter life expectancies than do those without mental illness. Patients with organic mental illnesses, including dementia, experience reduced life expectancy, but the extent of reduction is reported to be smaller than that for other psychiatric disorders. Consequently, the age at death for patients with AD and other dementias is higher than for those with other psychiatric disorders.[39] The results of our study align with these previous findings.

Conclusion

We investigated whether dementia was accurately recorded as the main diagnosis or direct cause of death on death certificates, focusing on psychiatric hospitals with a high number of inpatients with dementia. Dementia including AD was not accurately recorded on death certificates and the actual mortality rate for dementia including AD was estimated to be higher than currently reported. These findings underscore the critical need to increase awareness about dementia as a cause of death and to educate the public and healthcare professionals on accurately documenting it on death certificates. To further validate the findings of this study, it is necessary to expand the scope of the research to include general hospitals and nursing care facilities in future investigations and to examine the actual conditions more comprehensively.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Disclosure

The authors declare no conflicts of interest in this work.

References

1. Nichols E, Steinmetz JD, Vollset SE. GBD. 2019 dementia forecasting collaborators. estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the global burden of disease study 2019. *Lancet Public Health*. 2022;7(2):e105–e125. doi:10.1016/S2468-2667(21)00249-8
2. Prince M, Wimo A, Guerchet M, et al. *World Alzheimer Report 2015: The Global Impact of Dementia*. London, UK: Alzheimer's Disease International; 2015.
3. Crowell V, Reyes A, Zhou SQ, et al. Disease severity and mortality in Alzheimer's disease: an analysis using the U.S. National Alzheimer's coordinating center uniform data set. *BMC Neurol*. 2023;23(1):302. doi:10.1186/s12883-023-03353-w
4. Todd S, Barr S, Passmore AP. Cause of death in Alzheimer's disease: a cohort study. *QJM*. 2013;106(8):747–753. doi:10.1093/qjmed/hct103
5. Mölsä PK, Marttila RJ, Rinne UK. Survival and cause of death in Alzheimer's disease and multi-infarct dementia. *Acta Neurol Scand*. 1986;74(2):103–107. doi:10.1111/j.1600-0404.1986.tb04634.x
6. Parker D, Lewis J, Gourlay K. Palliative care and dementia. *Dement Aust*. 2017. Available from https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/05/Dementia-Aus-Palliative-Care-Discussion-Paper-36pp-R5.pdf. Accessed February 2023.
7. The National Hospice Organization Standards and Accreditation Committee Medical Guidelines Task Force. Medical guidelines for determining prognosis in selected non-cancer diseases. *Hosp J*. 1996;11(2):47–63. doi:10.1080/0742-969X.1996.11882820
8. World Health Organization (WHO). Global health estimates: leading causes of death. Available from: https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates/ghe-leading-causes-of-death. Accessed December 2023.
9. Statistics of Japan. Available from: https://www.e-stat.go.jp/en/stat-search/files?page=1&layout=datalist&toukei=00450011&tstat=000001028897&cycle=7&year=20220&month=0&tclass1=000001053058&tclass2=000001053061&tclass3=000001053065. Accessed December, 2023.
10. Hayashi R, Imanaga T, Marui E, et al. Senility deaths in aged societies: the case of Japan. *Glob Health Med*. 2024;6(1):40–48. doi:10.35772/ghm.2023.01127
11. Imanaga T, Toyama T. Survey on the diagnosis of senility as the cause of death in home medical care. *Jpn Prim Care Assoc*. 2018;41(4):169–175.
12. Taylor C, Greenlund S, McGuire L, et al. Deaths from Alzheimer's disease—United States, 1999-2014. *MMWR Morb Mortal Wkly Rep*. 2017;66(20):521–526. doi:10.15585/mmwr.mm6620a1
13. Stokes AC, Weiss J, Lundberg DJ, et al. Estimates of the association of dementia with US mortality levels using linked survey and mortality records. *JAMA Neurol*. 2020;77(12):1543–1550. doi:10.1001/jamaneurol.2020.2831
14. Ministry of health, labour and welfare. Available from: https://www.mhlw.go.jp/toukei/saikin/hw/kanja/20/index.html. Accessed December 2023.
15. Ministry of Health, Labour and Welfare. *Handbook of Health and Welfare Statistics 2023*. Available from: https://www.mhlw.go.jp/english/database/db-hh/2-2.html. Accessed December, 2023.
16. Okayama T, Usuda K, Okazaki E, et al. Number of long-term inpatients in Japanese psychiatric care beds: trend analysis from the patient survey and the 630 survey. *BMC Psychiatry*. 2020;20(1):522. doi:10.1186/s12888-020-02927-z
17. Toba K. Japan's new framework on dementia care. *Innov Aging*. 2021;5(Suppl 1):383. doi:10.1093/geroni/igab046.1487
18. Brunnstrom HR, Englund EM. Cause of death in patients with dementia disorders. *Eur J Neurol*. 2009;16(4):488–492. doi:10.1111/j.1468-1331.2008.02503.x
19. Burns A, Jacoby R, Luthert P, et al. Cause of death in Alzheimer's disease. *Age Ageing*. 1990;19(5):341–344. doi:10.1093/ageing/19.5.341
20. Ives DG, Samuel P, Psaty BM, et al. Agreement between nosologist and cardiovascular health study review of deaths: implications of coding differences. *J Am Geriatr Soc*. 2009;57(1):133–139. doi:10.1111/j.1532-5415.2008.02056.x
21. Romero JP, Benito-Leon J, Louis ED, et al. Underreporting of dementia deaths on death certificates: a systematic review of population-based cohort studies. *J Alzheimers Dis*. 2014;41(1):213–226. doi:10.3233/JAD-132765
22. UK Government. Guidance for doctors completing medical certificates of cause of death in England and Wales (accessible version). Available from: https://www.gov.uk/government/publications/guidance-notes-for-completing-a-medical-certificate-of-cause-of-death/guidance-for-doctors-completing-medical-certificates-of-cause-of-death-in-england-and-wales-accessible-version. Accessed December, 2023.
23. Statistics Canada. *Canadian Vital Statistics Death Database: Data Dictionary and User Guide 2013*; 2017.
24. Ganguli M, Rodriguez EG. Reporting of dementia on death certificates: a community study. *J Am Geriatr Soc*. 1999;47(7):842–849. doi:10.1111/j.1532-5415.1999.tb03842.x

25. James BD, Leurgans SE, Hebert LE, et al. Contribution of Alzheimer disease to mortality in the United States. *Neurology*. 2014;82(12):1045–1050. doi:10.1212/WNL.0000000000000240
26. Désesquelles A, Demuru E, Salvatore MA, et al. Mortality from Alzheimer's disease, Parkinson's disease, and dementias in France and Italy: a comparison using the multiple cause-of-death approach. *J Aging Health*. 2014;26(2):283–315. doi:10.1177/0898264313514443
27. Ministry of Health. Labour and welfare. manual to fill in a death certificate: Available from: https://www.mhlw.go.jp/toukei/manual/dl/manual_r03.pdf. Accessed December, 2024.
28. Centers for Disease Control and Prevention. Physicians' handbook on medical certification of death. Available from: https://www.cdc.gov/nchs/data/misc/hb_cod.pdf. Accessed December, 2024.
29. Hayashi R, Beppu M, Ishii F, et al. Statistical analysis of senility death in Japan. *J Popul Probl*. 2023;78(1):1–18.
30. Lin CE, Chung CH, Chen LF, et al. Increased risk of dementia in patients with schizophrenia: a population-based cohort study in Taiwan. *Eur Psychiatry*. 2018;53:7–16. doi:10.1016/j.eurpsy.2018.05.005
31. Harrison PJ. The neuropathology of schizophrenia: a critical review of the data and their interpretation. *Brain*. 1999;122(4):593–624.
32. Radhakrishnan R, Butler R, Head L. Dementia in schizophrenia. *Adv Psychiatr Treat*. 2012;18(2):144–153. doi:10.1192/apt.bp.110.008268
33. Tsuang MT, Stone WS, Faraone SV. Toward reformulating the diagnosis of schizophrenia. *Am J Psychiatry*. 2001;158(5):670–676.
34. McKeith IG, Cummings J. Behavioural changes in dementia with Lewy bodies. *Lancet Neurol*. 2005;4(1):19–27.
35. Villar J, Pérez-Méndez L. Evaluating an educational intervention to improve the accuracy of death certification among trainees from various specialties. *BMC Health Serv Res*. 2007;7(1):183. doi:10.1186/1472-6963-7-183
36. Goldman ML, Mangurian C, Corbeil T, et al. Medical comorbid diagnoses among adult psychiatric inpatients. *Gen Hosp Psychiatry*. 2020;66:16–23.
37. Kiviniemi M, Suvisaari J, Pirkola S, et al. Regional differences in five-year mortality after a first episode of schizophrenia in Finland. *Psychiatr Serv*. 2010;61(3):272–279. doi:10.1176/ps.2010.61.3.272
38. Owens DG, Cunningham EC, Johnstone EC. Treatment and management of schizophrenia. In: Gelder M, editor. *New Oxford Textbook of Psychiatry*. 2nd ed ed. Oxford, UK: Oxford University Press; 2012.
39. Peritogiannis V, Ninou A, Samakouri M. Mortality in schizophrenia-spectrum disorders: recent advances in understanding and management. *Healthcare*. 2022;10(2366):2366. doi:10.3390/healthcare10122366