

Reporting of Dementia Causes of Death among Nursing Home Residents

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Background:

Dementia, including Alzheimer's disease and other dementias, presents a major public health challenge in the United States. Dementia is characterized by memory impairment and cognitive decline. Alzheimer's disease is the most common cause of dementia. Other dementias, including Lewy body dementia, frontotemporal degeneration, vascular dementia and mixed dementias, are often indistinguishable from Alzheimer's disease in their symptoms and outcomes and may coexist with Alzheimer's disease. (National Institute on Aging 2016; U.S. Department of Health and Human Services 2017). The prevalence of dementia rises sharply with age, and an estimated 50-60% of nursing home residents have dementia (Centers for Medicare and Medicaid Services 2013). Nevertheless, it is not always recognized as a terminal illness (Mitchell et al. 2009).

A forthcoming NCHS report explores trends and patterns in dementia mortality and illustrates variability in reporting of Alzheimer's disease and other dementias in vital statistics data (Kramarow and Tejada-Vera 2018). It is not clear why some deaths are attributed to Alzheimer's disease while others are attributed to unspecified dementia or other dementia causes. From death certificates alone, it is not possible to know whether the decedent had a diagnosis of dementia before death. Mortality data linked to medical information can help us understand whether having a specific dementia diagnosis before death affects the reporting of causes of death on the death certificate.

Objectives:

This paper uses a linked data source to analyze the causes of death for decedents who were nursing home residents prior to death. We investigate how demographic characteristics and diagnoses (including dementia) are related to the underlying and multiple causes of death listed on the death certificate. We demonstrate the benefits and limitations of linked data for mortality analyses.

Data:

This research uses the 2004 National Nursing Home Survey (NNHS) linked to the National Death Index (NDI). This data set is one of several created by the National Center for Health Statistics to link administrative records to survey data to enhance the value of population-based surveys for scientific research (NCHS 2017). The 2004 NNHS is a sample survey of U.S. nursing homes, their services, staff, and residents. The resident files were linked to NDI death certificate records from 2004 through December 31, 2015. These data are unique because nearly all of the sample persons are eligible for linkage, avoiding the issue of selection bias that is common with linked data sets.

The key variables of interest from the NNHS are: Age at Admission, Age at Interview, Sex, Race, Hispanic Origin, Length of Stay, Special Unit (dementia), Primary Diagnosis at Admission (up to 2), Current primary diagnosis (up to 2), Current Secondary Diagnosis (up to 15), Date of Admission, Date of Interview). The key variables from the NDI are: Eligibility Status, Mortality Status, Date of Death, Underlying Cause of Death, Multiple Cause of Death

(Entity Axis and Record Axis), Number of Record Axis Conditions, Place of Death (from restricted additional variables), Autopsy (from restricted additional variables).

Methods:

The paper shows descriptive statistics of the NNHS-NDI sample who were eligible for linkage to mortality records. Logistic models identify which variables have a statistically significant relationship to the various causes of dementia death. We model the relationships to both underlying causes of death and to contributing causes of death. We also model the relationship between dementia diagnosis and other (non-dementia) causes of death. Dementia diagnosis in the nursing home is ascertained by selecting current diagnosis codes according to the ICD-9 codes listed by the CMS Chronic Conditions Warehouse (CCW) criteria for “Alzheimer’s disease and Related Disorders or Senile Dementia” (Centers for Medicare and Medicaid Services 2018). We model the relationship between the order of mention of dementia causes in the entity axis to the selection of dementia as an underlying or contributing cause of death.

Preliminary Results:

Nearly all (13,482/13,507) of the sample persons from the 2004 NNHS resident file are eligible for linkage to the NDI. Approximately 92% of those eligible sample persons were matched to death certificate records by December 31, 2015 (12,443/13,482). Cause of death information is available for nearly all the sample presumed dead (12,385/12,443). Nearly half (47% unweighted) of the sample of decedents with cause of death information had a dementia diagnosis before death during their nursing home stay (5829/12,385). Approximately one-third of nursing home residents with a dementia diagnosis during their nursing home stay, who died by December 31, 2015, had dementia recorded as an underlying cause of death on their death certificate. The implications for cause-of-death coding of dementia are discussed as well as the “lessons learned” from using linked data.

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