



Comparing Two Sources of Place of Death Data for People with Alzheimer’s Disease and Other Dementias in the United States

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Background:

Place of death is an important quality of life characteristic that is often left unacknowledged or undecided. In the context of Alzheimer’s Disease and other dementias, it is important for patients and caregivers to consider end-of-life care wishes and plans before total loss of decision-making capacity. The Centers for Disease Control (CDC) Wide-ranging Online Data for Epidemiologic Research (WONDER) database aims to promote information-driven decision-making by simplifying access to public health information for researchers and the public. This study evaluates the trends of place of death for patients with Alzheimer’s Disease and other dementias.

Methods:

This study includes data for all decedents from calendar year 2018 who died with a diagnosis of Alzheimer’s disease and other dementias using death certificate records from the Centers for Disease Control (CDC) Wide-ranging Online Data for Epidemiologic Research (WONDER) multiple cause of death data and linked administrative, claims, and assessment data from the Centers for Medicare & Medicaid Services (CMS) Chronic Conditions Data Warehouse (CCW). Descriptive analyses focused on demographic variables and place of death.

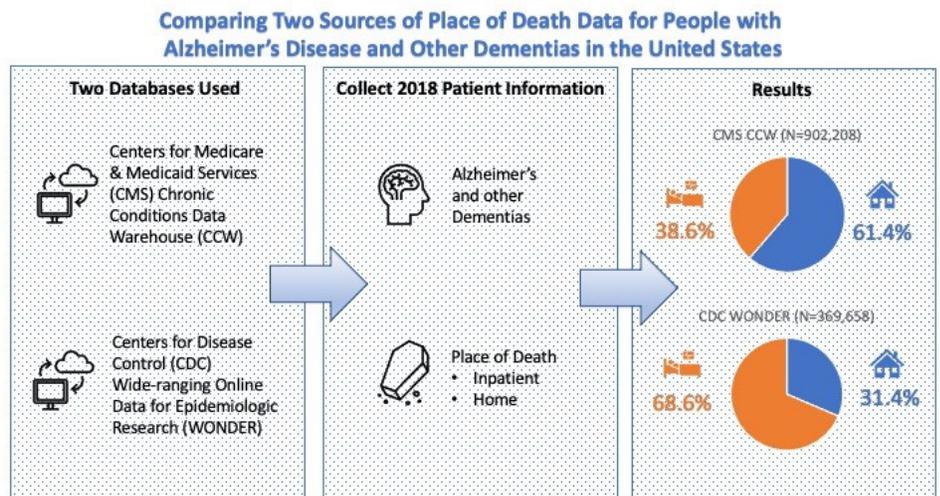
Results:

For the year 2018, CDC WONDER records 369,658 decedents with Alzheimer’s disease or dementia (ICD-10 codes: F01, F03, G30) while the CMS CCW includes 902,208 decedents with Alzheimer’s disease or other dementias. Among decedents with dementia in the CDC WONDER data, 116,197 (31.4%) died at home and 253,461 (68.6%) died in an inpatient setting. Among decedents with dementia in the CMS CCW data, 553,794 (61.4%) died at home and 348,414 (38.6%) died in an inpatient setting. Compared to the CMS data, the CDC data included slightly more non-Hispanic white decedents (82.9% vs. 82.1%) and slightly fewer Black decedents (8.4% vs. 9.7%) with dementia at death.

Conclusion:

Using the Centers for Medicare and Medicaid Services (CMS) data we counted more than twice the number of decedents with dementia in 2018

compared to the CDC WONDER multiple cause of death data for the same year. With respect to place of death, using the CDC WONDER data it appears that most people with dementia are dying in an inpatient setting (68.6%), however we observed the opposite pattern using the CMS CCW data, where most people with dementia were found to be dying in a home setting (61.4%). In combination with more nuanced and in-depth research, these findings can help inform public health policy regarding strategies to improve end-of-life care for people living with dementia.



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