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Mortality and mortality disparities among people with epilepsy in the United States, 2011–2021

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Abstract

Studies on epilepsy mortality in the United States are limited. We used the National Vital Statistics System Multiple Cause of Death data to investigate mortality rates and trends during 2011–2021 for epilepsy (defined by the *International Classification of Diseases, 10th Revision*, codes G40.0–G40.9) as an underlying, contributing, or any cause of death (i.e., either an underlying or contributing cause) for U.S. residents. We also examined epilepsy as an underlying or contributing cause of death by selected sociodemographic characteristics to assess mortality rate changes and disparities in subpopulations. During 2011–2021, the overall age-standardized mortality rates for epilepsy as an underlying (39% of all deaths) or contributing (61% of all deaths) cause of death increased 83.6% (from 2.9 per million to 6.4 per million population) as underlying cause and 144.1% (from 3.3 per million to 11.0 per million population) as contributing cause ($P < 0.001$ for both based on annual percent changes). Compared to 2011–2015, in 2016–2020 mortality rates with epilepsy as an underlying or contributing cause of death were higher overall and in nearly all subgroups. Overall, mortality rates with epilepsy as an underlying or contributing cause of death were higher in older age groups, among males than females, among non-Hispanic Black or non-Hispanic American Indian/Alaska Native persons than non-Hispanic White persons, among those living in the West and Midwest than those living in the Northeast, and in nonmetro counties compared to urban regions. Results identify priority subgroups for intervention to reduce mortality in people with epilepsy and eliminate mortality disparity.

Keywords

Epilepsy; Mortality; Disparity; Surveillance; Population

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Author Contributions

Niu Tian: Conceptualization, Validation, Formal Analysis, Writing − Original Draft, Visualization. **Rosemarie Kobau:** Conceptualization, Writing – Review & Editing. **Daniel Friedman**: Conceptualization, Writing – Review & Editing. **Yong Liu**: Conceptualization, Methodology, Writing – Review & Editing. **Paul I. Eke**: Conceptualization, Methodology, Writing – Review & Editing. **Kurt J. Greenlund**: Conceptualization, Methodology, Writing – Review & Editing, Supervision. All authors have read and approved the submitted manuscript.

1. Introduction

People with epilepsy have an increased rate of mortality compared to the general population [1,2]. In high-income countries, population-based studies suggest that standardized mortality ratios range from 1.6 to 3.0 [2]. In the United States, studies on epilepsy mortality are limited, and reported mortality trends among people with epilepsy vary, likely associated with different methodologies [3–5]. Other factors could also affect trends in epilepsy mortality, such as the impact of new therapies [6], changes in the population size with epilepsy [3,7], changes in the contribution of comorbidity-associated deaths [8,9], and changes in epilepsy case ascertainment [6,10,11]. We used the most recent available U.S. National Vital Statistics System (NVSS) mortality data from 2011 to 2021 to: (1) estimate numbers of deaths and age-standardized epilepsy mortality rates; (2) assess trends for epilepsy as an underlying, contributing, or any cause of death (i.e., either an underlying or a contributing cause); (3) examine differences in age-specific and age-standardized epilepsy mortality rates by selected sociodemographic characteristics (sex, race and ethnicity, region, and urban-rural status), with epilepsy as an underlying or contributing cause of death.

2. Methods

Mortality data based on information from death certificates for U.S. residents in 50 states and the District of Columbia are collected by the National Center for Health Statistics (NCHS) and compiled in NVSS. Each death certificate contains a single underlying cause of death (i.e., disease or injury that initiated the events resulting in death) and up to 20 additional contributing causes (i.e., significant conditions contributing to death but not resulting in the underlying cause). These public-use mortality data are available through the CDC WONDER (Centers for Disease Control and Prevention Wide-ranging Online Data for Epidemiologic Research) system (https://wonder.cdc.gov/). Institutional review board approval was not required for analysis of these publicly available data.

CDC WONDER Multiple Cause of Death data are divided into two separate files to account for revised standards for collecting and reporting racial and ethnic status. Notably, the 1999–2020 data file includes four bridged race categories, and the 2018–2021 data file includes six single race categories. We queried the 1999–2020 files with the bridged race categories to obtain epilepsy mortality data for number of deaths and standardized mortality rates for 2011–2020. We queried the 2018–2021 file with single race categories to obtain the most recent mortality data for 2021 only. Mortality rates are comparable for the time period of 2011–2021 overall and for sex, age, and region groups. However, racial/ethnic categories are not comparable between 2011–2020 and 2021 and therefore cannot be directly compared. Additionally, for urban-rural status, age-adjusted mortality rates were not available for 2021. Epilepsy was defined by the *International Classification of Diseases, 10th Revision*, codes G40 (G40.0–G40.9) as an underlying, contributing, or any cause of death. Rates were expressed as the number per million population and standardized to the year 2000 U.S. standard population. Trends were assessed with Joinpoint regression models (Joinpoint Regression Program, version 4.9.0.0, National Cancer Institute) [12]. Annual percent change (APC) was calculated as $APC_i = [(\text{Exp}(b_i) - 1)] \times 100$ where b_i represents the slope of the period segment (b represents an estimate of regression coefficient, i.e., a slope of the

trend, or a percent change of the rate in year *i*+1; i represents year) [13]. T-test was used to examine the null hypothesis that the estimated APC was equal to zero at the alpha level of 0.05. Significant changes in the estimated APC in mortality rate were assessed by a Monte Carlo permutation method and a grid search method to fit the simplest model with the minimum number of line segments [14].

We obtained unadjusted (crude) and age-standardized mortality rates for overall mortality. We also obtained age-specific and age-standardized mortality rates with 95% confidence intervals (CIs) by sex, race/ethnicity, region, and urban-rural status. For the 2011–2020 timespan, we stratified years by two time periods (2011–2015 and 2016–2020) to increase sample sizes—in order to examine differences in mortality rates in the selected subgroups. Differences in mortality rates by the two time periods, and within demographic groups (compared to selected reference groups), were examined using two-tailed Z-tests with alpha = 0.05 [15]. Because racial/ethnic categories for 2021 are not comparable to those in earlier years, and age-standardized rates for urbanization categories are not available for 2021, we present and discuss 2021 results separately where appropriate.

3. Results

For the period 2011–2021 overall, 43,231 deaths were reported with epilepsy as any cause of death. Among them, 16,741 (38.7%) were reported with epilepsy as the underlying cause of death (Supplemental Table 1), and 26,490 (61.3%) were reported with epilepsy as a contributing cause of death (Supplemental Table 2). Mortality rates per million population significantly increased from 2011 to 2021 for epilepsy as an underlying (2.9 [CI: 2.7–3.1] to 6.4 [CI: 6.1–6.7]); contributing (3.3 [CI: 3.1–3.4] to 11.0 [CI: 10.7–11.4]); and any cause (6.2 [CI: 5.9–6.5] to 17.4 [CI: 17.0–17.9]) (all $P < 0.001$) (Figure). Notably, mortality rates showed marked increases from 2019 to 2020, and the upward trend continued in 2021. The average APCs from 2011 to 2021 were 7.6, 13.1, and 10.7 for epilepsy as an underlying, contributing, or any cause of death, respectively. Overall, based on APCs, mortality rates increased 83.6% as an underlying cause of death and 144.1% as a contributing cause of death.

Compared to 2011–2015, the age-standardized mortality rate with epilepsy as an underlying cause of death during 2016–2020 was greater overall and in all subgroups (age, sex, race/ethnicity, region, and urban-rural status) except among non-Hispanic American Indian/Alaska Native persons (Supplemental Table 1). For the overall period 2011–2020, and within each time period, the age-specific mortality rate was lowest in the youngest age group and increased with each successive age group. The age-standardized mortality rate was higher in males than females. Age-standardized mortality rates were higher among non-Hispanic Black and non-Hispanic American Indian/Alaska Native persons and lower among non-Hispanic Asian/Pacific Islander persons compared to non-Hispanic White persons. Age-standardized mortality rates with epilepsy as an underlying cause were lowest in the Northeast and highest in the West and Midwest. Compared to those living in large central metro counties, age-standardized mortality rates were higher among those living in nonmetro counties (except during 2011–2015) but lower among those living in large fringe metro areas, which had the lowest mortality rates.

For those with epilepsy as a contributing cause of death (Supplemental Table 2), similar results were observed by selected characteristics, although the rate increased more markedly with age. The mortality rate among those aged ≥ 65 years was 11-fold higher than among those aged ≤ 24 years during 2011–2020.

Mortality rate patterns by age and sex for 2021 alone were similar to those observed for 2011–2020. However, in 2021, the age-standardized mortality rate was higher for non-Hispanic Black persons compared to non-Hispanic White persons. Non-Hispanic Asian/Pacific Islander persons had the lowest mortality rate among all race/ethnicity subgroups (Supplemental Tables 1 and 2).

4. Discussion

Death rates with epilepsy listed as an underlying, contributing, or any cause increased significantly in the United States during 2011–2021, surging from 2019 to 2020 and into 2021. Overall, older persons, males, non-Hispanic Black or non-Hispanic American Indian/Alaska Native persons, those living in the West and Midwest, and those living in rural counties had the highest mortality rates. Using the latest data available, our study extends previous work [3–5] and provides additional information on differences in epilepsy mortality over an expanded timeframe and by region and urbanicity.

Reasons for the increasing U.S. epilepsy mortality rates during 2011–2021 are not fully understood. It is likely that increased recognition and documentation of epilepsy history (e.g., as a contributing cause of death) among medical examiners and forensic pathologists, neurologists, family members and others have followed recent efforts in the field of epilepsy to develop and disseminate guidelines and recommendations to improve epilepsy case ascertainment for death investigation and certification [11, 16]. An increase in recognition and reporting would result in greater rates of epilepsy related mortality even without changes in the incidence of epilepsy. Another possible reason for the increased number of epilepsy cases may be attributed to the general population growth [7] and an aging population, as well as the improved survival rate among children. The aging U.S. population [17] includes more older people developing age-related epilepsy risk factors [10] like stroke or dementia [18,19]. Conversely, in children, an increased number of epilepsy cases could be attributed to improved survival rates for children with early life brain injuries [20,21]. The rising number of epilepsy cases and associated deaths, coupled with the increased recognition of comorbidity-associated deaths among people with an epilepsy history [3,4,8,9] (such as psychiatric disorders, suicide, and dementia [8–10]), may contribute to an increase in epilepsy mortality rates. In addition, it is possible that advances in genetic testing in children with developmental and epileptic encephalopathies and/or rare epilepsies could also enhance the recognition of epilepsy-related deaths [8,22]. Further assessment is needed for more specific causes of death with epilepsy as the underlying cause of death or contributing cause of death.

COVID-19 likely contributed to the surge in epilepsy mortality rates during 2019 to 2021. COVID-19 was ranked as the third leading underlying cause of death in both 2020 and 2021 in the U.S. general population [23,24]. From 2019 to 2020, the overall age-adjusted

mortality rate increased 15.9%, and COVID-19 (reported as the underlying or contributing cause of death) accounted for 11.3% of total deaths in 2020 [23]. The overall mortality rate further increased by 0.7% from 2020 to 2021, and COVID-19 accounted for 13.3% of total deaths in 2021 [23]. Studies have shown that the COVID-19 pandemic presented unique challenges to people with epilepsy, including increased seizure rates, barriers to obtaining necessary health care [25], and increased hospitalizations and death compared to the general population [26]. At least one population-based study reported an increase in COVID-19–related deaths associated with epilepsy [27]. A U.S. population-based study using 2021 data found suboptimal COVID-19 vaccination status among adults aged 18–44 years with active epilepsy [28]. This study, along with our data, highlights the need to promote COVID-19 vaccinations among people with epilepsy to prevent adverse health outcomes or death.

Our study found that among all deaths with any mention of epilepsy, most (61%) were due to other causes of death with epilepsy listed as a contributing cause of death. This finding underscores comorbidity-associated deaths among people with an epilepsy history, suggesting the importance of elevating comorbidity prevention for those with epilepsy or with an epilepsy history—to potentially reduce mortality in people with epilepsy [8,29]. Our study also identified priority subgroups for intervention. For example, the higher mortality rate among those aged ≥ 65 years likely reflects the fact that epilepsy incidence and prevalence increase after middle age [30], probably due to increased common chronic and progressive neurologic disorders such as cerebrovascular disease and dementia [17,18], or other related diseases in older adults [3,17]. Developing, validating, and disseminating screening tools for the early identification of epilepsy and its comorbidities in older adults, and use of these tools by clinicians [31], could benefit people with epilepsy by reducing comorbidities and related deaths [32].

Higher mortality rates associated with epilepsy (with epilepsy as either an underlying cause or a contributing cause) were found among non-Hispanic Black and non-Hispanic American Indian/Alaska Native populations. Long-standing racial/ethnic disparities in epilepsy knowledge, treatment, and access to care have been reported [33–37]. Differences in health care use and patterns of care associated with race/ethnicity, low income, insurance status, and site of care have been previously reported for people with epilepsy [38,39]. Such socioeconomic factors could partially explain mortality disparities by race/ethnicity. Accessible transportation, another social determinant of health, is particularly important for people with epilepsy, who often cannot drive. Insufficient transportation is a key barrier for patients, deterring access to epilepsy appointments [40,41]. Insufficient transportation may disproportionately affect non-Hispanic American Indian/Alaska Native individuals residing in rural areas [42], contributing to suboptimal care and increased mortality in this group. Finally, the prevalence of acute and chronic conditions in non-Hispanic American Indian/Alaska Native and non-Hispanic Black persons is highest among all racial/ethnic groups [29]. The presence of comorbid conditions, coupled with the aforementioned factors, can further complicate treatment decisions, affect outcomes, and contribute to mortality disparity in racial/ethnic subgroups. A multifaced approach is required to eliminate these disparities [43], including addressing social-cultural factors, promoting equitable access to care, and mitigating physiological processes in disease development and management (e.g., epilepsy-related comorbidities).

Our study found higher mortality rates in the West and Midwest compared to the Northeast, consistent with a recent report suggesting that level IV epilepsy centers are clustered in the Northeast and scarce in the West and Midwest [44]. This, along with our finding that mortality rates are higher in nonmetropolitan areas than urban regions, underscores the significance of geography, particularly related to the availability of epilepsy health care. Enhanced access to health care providers and epilepsy specialty care in remote and rural areas is warranted. This can be achieved by optimizing the use of telehealth, expanding health care infrastructure [43,44], offering epilepsy training to more primary care providers, and exploring policy interventions to facilitate access to epilepsy specialty care.

This study is subject to at least three limitations. First, this study analyzed deaths from epilepsy as recorded on death certificates, and epilepsy may not always be recognized as a cause of death (underestimated) [45], especially for those deaths with epilepsy listed as a contributing cause. Additionally, sudden unexpected death in epilepsy (SUDEP), a leading epilepsy-related causes of death [10], is not captured in the NVSS because there is no ICD-10 code for SUDEP, or SUDEP is misclassified (e.g., attributed to other more common diseases such as cardiovascular diseases [10,16]). This may have led to an underestimation of epilepsy-related deaths. However, given the relatively small numbers of SUDEP cases in the general population, it's unlikely this biased study findings. Second, most decedents in the United States are not autopsied [46], so the cause of death among people with epilepsy could be misclassified. Third, in separately reported 2021 data, racial/ethnic categories are not comparable to corresponding categories in prior years, and age-standardized rates by urban-rural status were not available.

5. Conclusions

Our findings, in a large national sample of the U.S. population, highlight the increasing epilepsy mortality rates and epilepsy mortality disparities, as well as the need for individual-, organizational-, and community-level interventions to reduce epilepsy-associated mortality. The use of existing resources such as stroke, suicide, and injury prevention programs—and efforts to improve access to health care and address social determinants of health—may reduce overall mortality and eliminate mortality disparities among people with epilepsy in the U.S. population.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Declarations of interest

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Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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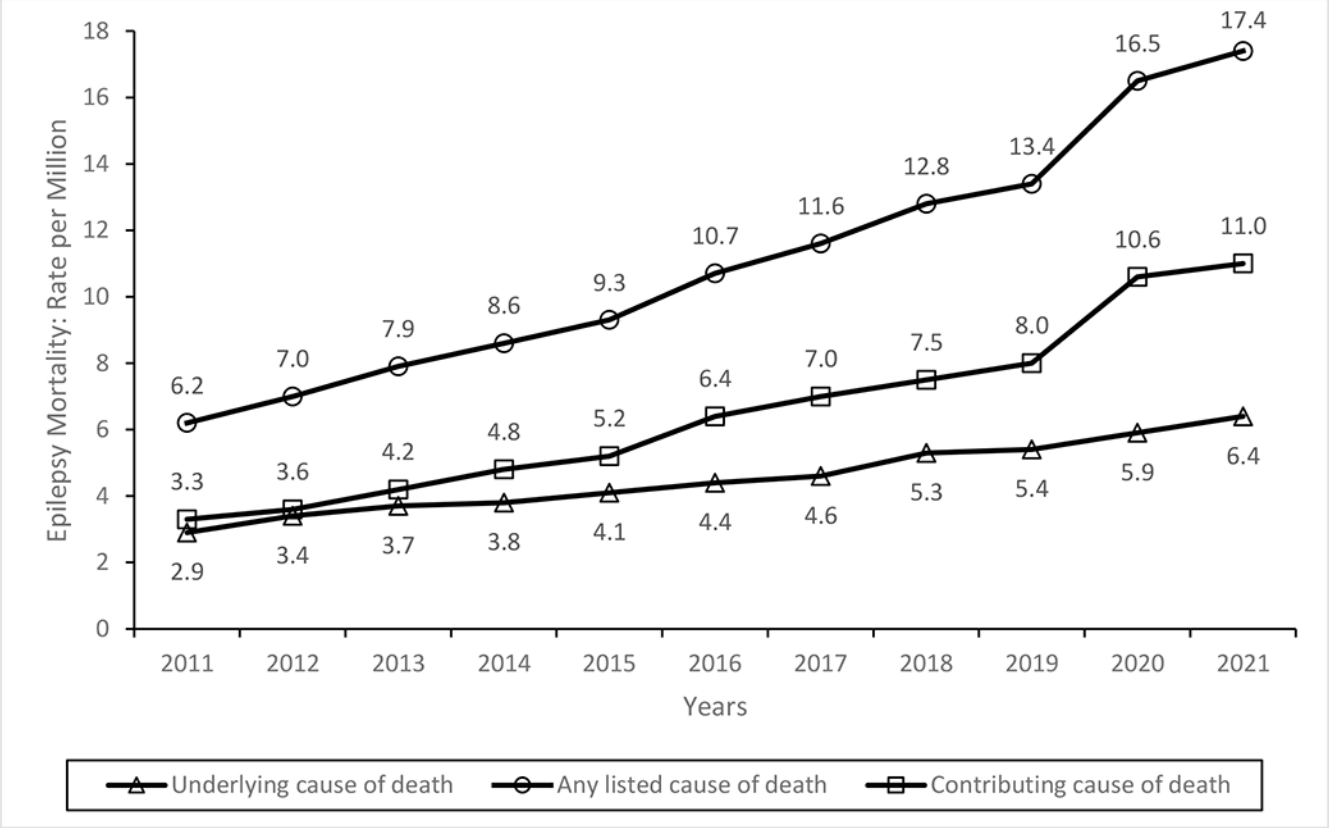

Figure:

Trends in age-standardized epilepsy mortality rates as an underlying, contributing, or any listed cause of death—National Vital Statistics System, United States, 2011 to 2021.

The increase in slope from 2011 to 2021 was statistically significant for all rates (Joinpoint regression model indicated that annual percent change was significantly different from zero $P < 0.001$).