

Dementia Mortality Rates:
A Sustained and Disparate Increase for Caucasians and African Americans, 1999 – 2016.

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Abstract

Background: Racial disparities in dementia incidence, prevalence, and mortality have steadily increased over time.

Objective: Compare and contrast Caucasian and African American dementia mortality rates by time and age group in the United States.

Methods: Dementia mortality rates from 1999-2016 were compared by race and age using data from the CDC compressed mortality database.

Results: Dementia mortality rates in the United States increased for African Americans and Caucasians over the age of 65 years-old by 294% between 1999 and 2016. African Americans (50.8 deaths per 100,000) have higher reported mortality rates than Caucasians (44.2 deaths per 100,000) for individuals 65 to 74 years-old, while Caucasians have a higher overall mortality rate (428.8 per 100,000) than African Americans.

Conclusion: More refined diagnostic tools and surveillance practices should be developed to correctly diagnose dementia, administer care, and report dementia-related deaths.

Introduction

Dementia is defined as a syndrome of cognitive degeneration that progressively leads to the loss of functional and cognitive processes in affected individuals.¹ There are several dementia subtypes, the most common is Alzheimer's disease (AD) which contributes to two-thirds of dementia cases. AD affects more than five million people in the United States alone, and is the sixth leading cause of death in the United States according to the CDC.^{2,3} These high prevalence rates are believed to be an understatement, as researchers have found that the number of dementia deaths is likely much larger than the number of deaths recorded.⁴

Known risk factors for the development of dementia include age, race, gender, education attainment, and genetics.¹ Other diseases and medical events have also been shown to increase a person's likelihood of developing dementia, including sleep apnea, smoking, obesity, stroke, depression, and surgeries requiring anesthesia.⁵ Yet, these known factors do not fully explain why dementia incidence and mortality rates have been significantly increasing over time. The long, degenerative nature of this disease makes it difficult to conduct epidemiological studies, and there are not yet clearly defined diagnostic criteria for all varying forms of dementia. In particular, participation in clinical trials and intervention strategies are under-representative of African Americans, who have the highest prevalence of cognitive impairment over the age of 55.⁶

The purpose of this study is to assess the differences in race, age, and time characteristics of dementia mortality for Caucasians and African Americans. Furthermore, this study explores how

data collection and socioeconomic differences contribute to the trends and possible omissions observed in the mortality data.

Methods

Our study encompasses all Caucasian and African American dementia mortality rates from 1999 to 2016 in the United States. Data was collected from the CDC compressed mortality database, CDC Wonder⁷ for the following ICD-10 codes: vascular dementia (F01), unspecified dementia (F03) and other degenerative diseases of the nervous system (G30-G31). The majority of these deaths were categorized as ‘unspecified’. Given the known limitation of specificity in dementia mortality cases, all dementia-related deaths were analyzed at an aggregate level for this study.

Dementia mortality rates were evaluated by race, year, and age cohort, focusing on deaths that occurred at ages 65 years-old and above. In order to focus on the largest dementia mortality rates amongst races, Asian/Pacific Islanders and American Indian/Alaskan Natives were excluded from this study, as preliminary data assessments showed these groups have significantly lower dementia mortality rates compared to African Americans and Caucasians. To control for age, age-adjusted rates are used for data interpretation where possible.

To measure rate differences by race, Caucasian death rates per 100,000 were subtracted by African American death rates per 100,000. A 95% confidence interval (z-score of 1.96) was used to determine if rate differences were statistically significant. Relative risks were calculated as ratios of Caucasian deaths per 100,000 divided by African American deaths per 100,000. There were no suppressed death counts in our dataset.

Results

There were 2,923,443 total dementia mortality deaths across the Caucasian and African American groups from 1999 to 2016. Sixty-five percent of these deaths occurred in individuals 85-years-old and above, and 99% of deaths occurred in individuals 65 years-old and above. The overall age-adjusted dementia mortality rate in 1999 was 27.9 per 100,000; this rate more than doubled to 66.6 per 100,000 by 2016 (Figure 1). Based on age-adjusted rates, the number of deaths have increased similarly for both African Americans and Caucasians at a rate of 3.17 additional deaths per 100,000. Each year from 1999 to 2016, Caucasians sustained a higher overall age-adjusted mortality rate than African Americans relative risk by a factor of 1.05 to 1.41 (in 2012 and 1999 respectively).

In addition to race, mortality rates also vary significantly by age (Table 1). African Americans show a higher mortality in the 65 to 74 year-old age group by a relative risk factor of 1.15 and show a mortality rate difference (White – Black) of -6.6 [95% CI: -5.84, -7.36] deaths per 100,000. This rate relationship is the reverse of what we observe in the overall, aggregated mortality data by race alone. Looking further at mortality by age group, there is no statistical difference in deaths by race for 74 to 84 year-olds, and only in the 85+ age group do Caucasians report a higher mortality rate than African Americans. In the oldest age group of 85+, Caucasians have a mortality rate of 2,120.2 deaths per 100,000, which is a statistically significant, higher mortality rate than African Americans by 281.7 deaths per 100,000. Driven by the large number of Caucasian deaths that occur in the oldest age group of 85+, African Americans have a lower reported overall 65 year-old and above dementia mortality rate than Caucasians by a relative risk

factor of 0.79 and show a mortality rate difference of 90.6 [95% CI: 89.07, 92.13] deaths per 100,000.

Segmenting out the youngest age group in our analysis, 65 to 74 year-olds, the rate of dementia mortality is increasing at a faster rate for African Americans than Caucasians. Beginning in 2004, African American dementia mortality increased by 2.17 deaths per 100,000 each year, whereas Caucasian mortality has increased by only 1.63 deaths per 100,000. This rapidly increasing pattern of African American mortality for the youngest age group is not carried forward in older age groups and is overshadowed by the reported Caucasian deaths in the oldest age group.

Discussion

This study shows that dementia mortality increased over time from 1999 to 2016 for both African American (376%) and Caucasian individuals (229%) aged 65 years-old and above. According to the CDC, dementia morbidity rates are projected to double by 2060, therefore we expect dementia mortality rates to continue to rise over time.⁸ Based on our findings, dementia mortality increases with age, which is consistent with the literature and the degenerative nature of this fatal disease. For the 65 to 74 year-old age group, findings show that African Americans have significantly higher mortality rates than Caucasians, while, in the 85+ age cohort, Caucasians have a higher dementia mortality rate compared to African Americans. We found the literature, however, indicates that across the United States, African Americans are twice as likely to have dementia when compared to Caucasians;⁹ therefore, an overall higher dementia mortality rate in African Americans would be expected.

This point of discordance between our study's finding and the literature may be in part accounted for by the underdiagnosis of dementias or underreporting of dementia mortality within African American communities.⁴ Health inequities rooted in negative environmental, socioeconomic, and lifestyle factors are disproportionately impacting African Americans and contributing to dementia risk.¹⁰ African Americans also have a higher prevalence of a genetic predisposition marker, the APOE e4 allele, though this risk factor does not fully explain the group's elevated risk for dementia.¹¹ Furthermore, the racial disparity in age-specific mortality differences between African Americans and Caucasians may be contributing to the current increasing fatality of younger African Americans and older Caucasians from dementia. Studies show consistent and adverse disparities among African Americans compared to Caucasians concerning clinical trial participation, medication and intervention use, long-term services and supports use, health care expenditures, and quality of care, which all may contribute to more rapidly increasing African American dementia mortality rates.⁶

Strengths of our study include: a high statistical power due to the large number of dementia deaths, insight into dementia mortality trends that are generalizable to the overall United States, and reproducibility of results since all data is publicly available. There are several limitations that should be considered when interpreting the results of our study. Notably, by using a single, passive surveillance system to collect data, there is potential for missing and miscategorized death certificate data. Studies have found that death certificate data underestimates the occurrence of dementia due to poor reporting by medical personnel,⁴ and specific dementia types are commonly misclassified or not considered the primary cause of death for individuals with multiple comorbidities. Additionally, reporting is likely impacted by the determination of

whether dementia is an underlying or proximal cause of death. There is a greater likelihood that only proximal causes would be listed even when dementia was an underlying cause or condition. Another limitation is that death certificates lack socioeconomic data and place of residence history, which may have led to additional identification of environmental confounders.

Further research that explores methods to link dementia incidence rates and registry data with death certificate data would be instrumental in establishing an accurate representation of the risk, onset, diagnosis, and outcome of dementia across demographic groups.¹² Moreover, it is important to increase efforts to gather data on effective preventive interventions, as well as elucidating best practices for community-based dementia research and clinical trials in African American communities.

Conclusion

Given dementia mortality rates have been increasing over time with a sustained racial disparity between Caucasians and African Americans, more research is needed to develop better diagnostic tools and effective therapeutic treatments for dementia. Specifically, earlier detection and more refined surveillance processes to differentiate dementia types for patients, of all racial backgrounds, is important to combat dementia disparities. Considering our findings and the compounding challenges of the social health determinants, an immediate focus should be placed on securing access to dementia diagnostic work and care for African Americans over the age of 75. Finally, to improve the cause of death surveillance data, there is an urgent need to train medical personnel on the importance of correct coding and reporting procedures for dementia-

related deaths. Eliminating racial disparities in detection will become especially important as effective prevention and treatment strategies become available.

Acknowledgements

We would like to thank Dr. Patrick Remington, Dr. Maureen Durkin, Dr. Sabrina Murphy, and Pravleen Bajwa for their advice, encouragement, and feedback on this project throughout the semester.

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Appendix

Table 1. Crude Dementia Mortality Rates by Race and Age Group per 100,000 in the U.S., 1999 - 2016.

Age Group	White/ Caucasians	Black / African Americans	Rate Difference (White - Black)	95% Confidence Interval of Rate Difference	Relative Risk of Mortality Rates by Race (White Ref. Group)
65-74	44.2	50.8	-6.6	[-7.36, -5.84]	1.15*
75-84	361.3	360.9	0.4	[-2.42, 3.22]	1.00
85+	2,120.2	1,838.5	281.7	[271.02, 292.38]	0.87*
All Ages	428.8	338.2	90.6	[89.07, 92.13]	0.79*

*Denotes Statistical Significance at a 95% Confidence Level

Figure 1. Trends in age-adjusted dementia mortality rates in the United States, 1999 – 2016.

Age-adjusted to the 2000 U.S. population.

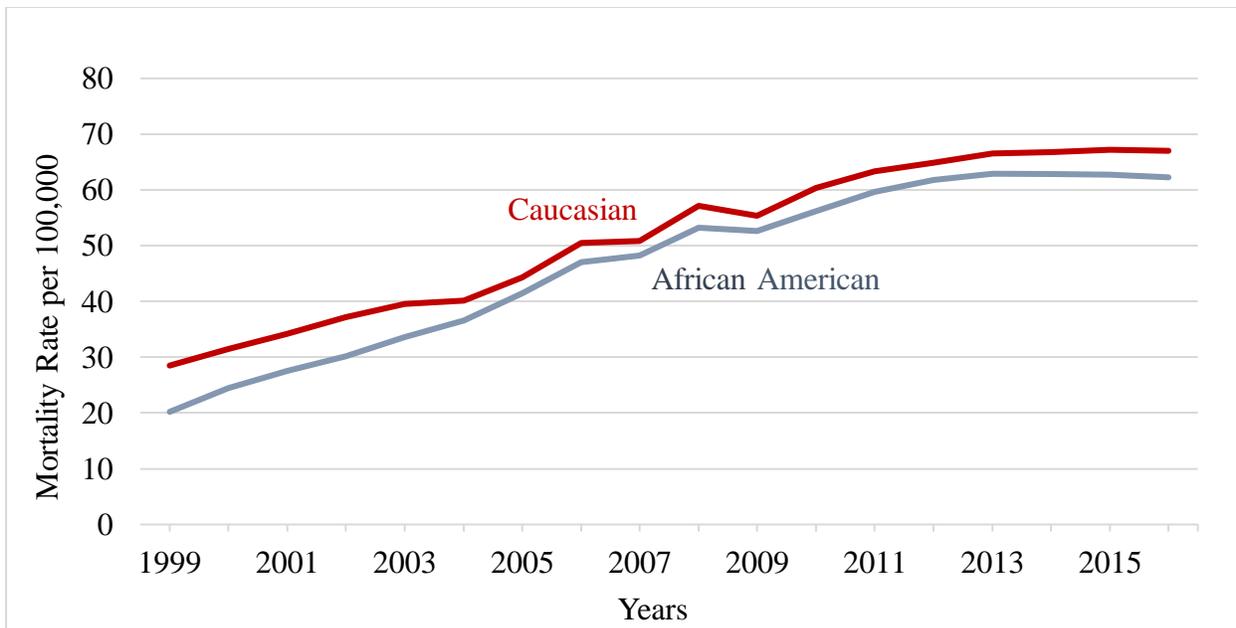


Figure 2. 65 to 74 Year-Old Crude Dementia Mortality Rates in the United States, 1999 – 2016.

