Systematic Review/Meta-analysis

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Trends in mortality and disparities in dilated cardiomyopathy across gender, race, and region in the United States (1999-2020)

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Background: Dilated cardiomyopathy (DCM) is a significant contributor to heart failure and sudden cardiac death in the United States. Understanding mortality trends associated with DCM is crucial to inform healthcare strategies and policy interventions to mitigate its burden.

Objectives: This study aimed to assess temporal trends in DCM-related mortality in the United States from 1999 to 2020, including an analysis of age-adjusted mortality rates (AAMRs), annual percent changes (APCs), and disparities across gender, racial/ethnic, geographic, and urbanization categories.

Methods: A retrospective observational study was conducted using data from the CDC WONDER database. DCM-related mortality was identified using the ICD-10 code I42.0. The study population included individuals in the United States with DCM listed as a contributing or primary cause of death from 1999 to 2020. AAMRs were calculated and standardized to the U.S. 2000 standard population. Joinpoint regression analysis was used to evaluate trends and calculate APCs and subgroup analyses were conducted to assess disparities.

Results: From 1999 to 2020, 168 702 deaths were attributed to DCM. The overall AAMR declined significantly from 9.33 per 100 000 individuals in 1999 to 6.61 in 2020 (APC: –3.43%, 95% CI: –4.09 to –2.70; $P < 0.001$). Males exhibited higher mortality rates (AAMR: 3.4) compared to females (AAMR: 1.5), with gender disparities persisting throughout the study. Blacks/African Americans and residents of the Western region experienced slower mortality declines compared to other groups. Geographic disparities were evident, with the Northeast showing the most significant drop (APC: –4.32%). In recent years, heart transplantation and advancements in Left Ventricular Assist Devices (LVADs) have significantly improved outcomes for end-stage DCM patients.

Conclusions: While DCM-related mortality declined significantly, persistent gender, racial, and regional disparities highlight the need for targeted interventions. The evolving role of heart transplantation and LVADs underscores the importance of equitable access to advanced therapies to reduce DCM-related mortality further.

Keywords: cardiomyopathy, CDC wonder, DCM, dilated cardiomyopathy, mortality

Introduction

DCM is a myocardial disorder characterized by left ventricular dilatation and systolic dysfunction, which frequently progresses to symptomatic heart failure. Clinically, DCM is associated with arrhythmias, thromboembolic events, and a high risk of sudden cardiac death (SCD)[1]. DCM contributes substantially to heart failure, with an estimated 1 to 2 million adults affected. The condition presents with significant morbidity and mortality, making it one of the leading causes of heart failure globally particularly in the United States[2].

The etiology of DCM is diverse, encompassing genetic, viral, autoimmune, and toxic factors. Genetic mutations have been found to account for approximately 40% of DCM cases, which underscores the importance of genetic testing for early diagnosis and risk stratification[3]. In addition to genetic influences, lifestyle factors such as alcohol abuse and metabolic disturbances contribute to the development of DCM[4]. Despite advancements in medical therapy, including the use of beta-blockers, angiotensin-converting enzyme inhibitors,

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and device-based interventions, the prognosis of DCM remains poor, with many patients eventually requiring heart transplantation[5]. Furthermore, heart transplantation and Left Ventricular Assist Devices (LVADs) have revolutionized the management of end-stage DCM, providing life-saving options for patients with advanced disease[6].

Epidemiological data suggests that DCM disproportionately affects males, older adults, and certain racial and ethnic groups, including African Americans[2]. The incidence and prevalence of DCM have been observed to increase over the past decades, raising public health concerns. In the United States, the prevalence of DCM was reported to be 118.33 per 100 000 individuals between 2017 and 2019[4]. Understanding trends in DCM-related mortality and identifying high-risk populations is crucial for developing targeted public health policies and improving clinical outcomes.

Using the CDC WONDER database, this study will comprehensively analyze trends in DCM-related mortality from 1999 to 2020. Specifically, it examines AAMRs, APCs, and disparities across gender, racial/ethnic, and geographic groups. By elucidating these trends, the study intends to inform healthcare professionals and policymakers regarding effective interventions to reduce DCM-related mortality and address healthcare disparities.

Methods

Study design and data source

This retrospective observational study utilized the Centers for Disease Control and Prevention (CDC) Wide-ranging Online Data for Epidemiologic Research (WONDER) database. The CDC WONDER database provides publicly accessible mortality and population data from death certificates collected across all U.S. states and the District of Columbia. This data source has been extensively used in epidemiological studies to analyze trends in mortality associated with various health conditions, including cardiovascular diseases[7].

Case definition

Mortality due to DCM was identified using the International Classification of Diseases, 10th Revision (ICD-10) code I42.0. This code explicitly represents DCM as the underlying cause of death. Deaths in which DCM was listed as a contributing or primary cause were included in the analysis.

Study population

The study population included all individuals in the United States who had DCM listed on their death certificates between 1999 and 2020. The analysis included data from all 50 U.S. states and the District of Columbia, providing a national overview of trends in DCM-related mortality. The demographic characteristics examined included sex, race/ethnicity, geographic region, and urban-rural classification. The population was categorized per the National Centre of Health Statistics Urban-Rural Classification Scheme; the urban areas contain large metropolitan areas with a population of 1 million or more and medium/small metropolitan areas ranging from 50 000 to 999 999[8]. Rural regions were classified as those of fewer than 50 000 people, and there were additional countries, as defined by the 2013 U.S. Census. According to the criteria of the United States Census Bureau, geographical categories are Northeast, Midwest, South, and West[9].

Variables and measures

The primary outcome measure was the AAMR per 100 000 individuals. AAMRs were calculated by standardizing mortality rates to the U.S. 2000 standard population to account for differences in age distributions over time. Additional measures included crude mortality rates, APCs in AAMRs, and stratified analyses by gender, race/ethnicity, geographic region, and urbanization status. Geographic regions were categorized based on the U.S. Census Bureau definitions: Northeast, Midwest, South, and West.

Statistical analysis

Joinpoint regression analysis was used to evaluate trends in DCM-related mortality over time. The Joinpoint Regression Program (version 5.0.2, National Cancer Institute) was utilized to identify significant changes in trends by fitting a series of log-linear models. The models allowed for the detection of points at which the trend in mortality rates changed significantly, termed "joinpoints." APCs were estimated to describe the magnitude and direction of trends within each segment. A two-sided *P* value of less than 0.05 was considered statistically significant. The analysis also included 95% confidence intervals (CIs) for APCs to assess the precision of the estimates. AAMR was calculated by standardizing DCM-related deaths in the United States in 2000.

Sensitivity analyses were conducted to assess the robustness of the findings. These included examining trends in specific subgroups, such as by race/ethnicity and urbanization status, to identify whether particular populations experienced different mortality trends compared to the overall population. All statistical analyses were performed under the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines to ensure methodological rigor and transparency.

Ethical considerations

This study used publicly available, de-identified data from the CDC WONDER database. As such, it did not require approval from an institutional review board or informed consent from participants. The data collection and analysis procedures adhered to the ethical standards established for epidemiological research involving secondary data.

Data abstraction and quality control

Data were abstracted from the CDC WONDER database, focusing on population size, year of death, place of death, demographic characteristics, and geographic location. Data quality control measures included cross-referencing the extracted data with CDC WONDER's data documentation to ensure completeness and accuracy. The completeness of death certificate reporting in the CDC WONDER database enhances the reliability of mortality estimates used in this study.

Results

Trends in overall DCM-related mortality

From 1999 to 2020, a total of 168 702 deaths were attributed to DCM in the United States (Supplementary Table 1, available at:

http://links.lww.com/MS9/A706). The overall AAMR for DCM declined significantly from 9.33 per 100 000 individuals in 1999 to 6.61 in 2020, corresponding to an APC of −3.43% (95% CI: −4.09 to −2.70, P < 0.001). Two significant periods of decline were identified: 1999 to 2002 (APC: −5.58%, 95% CI: −11.51 to −0.99) and 2005 to 2014 (APC: −6.93%, 95% CI: −11.34 to −5.63). The decline plateaued from 2014 to 2020, with minimal annual changes observed (Fig. 1; Supplementary Tables 3 and 4, available at: http://links.lww.com/MS9/A706). Regarding mortalities based on the place of death, most DCM-related deaths occurred in medical facilities, accounting for 48.57% of all deaths. A significant portion also occurred in the decedent's home (33.5%). Additionally, 11.7% of deaths were reported in hospice facilities and nursing homes, emphasizing the importance of end-of-life care in managing DCM (Supplementary Table 2, available at: http://links.lww.com/MS9/A706). Supplementary Tables 1 and 2 (available at: http://links.lww.com/MS9/A706) included the number of total mortalities, while Supplementary Tables 3 and 4 included the trends and AAMR.

Mortality trends by gender

Males consistently exhibited higher AAMRs compared to females throughout the study period. The overall APC for males was −3.52% (95% CI: −4.24 to −2.79), while for females it was −3.56% (95% CI: −4.54 to −2.68). Notably, a significant increase in female mortality was observed between 2001 and 2004 (APC: 8.56%, 95% CI: 0.48 to 14.40), followed by a sharp decline from 2004 to 2014 (APC: −6.57%, 95% CI: −11.37 to −5.58). In contrast, male mortality increased initially from 2002 to 2005, similarly to females, then decreased consistently during similar periods to females, with a notable decline between 2005 and 2015 (APC: −6.69%, 95% CI: −11.48 to −4.72). In summary, while both males and females saw declines, gender disparities persist, with males showing slower reductions post-2014 (Fig. 1). Trends and AAMRs over the years of study in genders are included in Supplementary Tables 3 and 4 (available at: http://links.lww.com/MS9/A706).

Mortality trends by race/ethnicity

Analysis by race/ethnicity indicated the highest mortality rates among Blacks/African Americans, followed by Whites, Asians/Pacific Islanders, and American Indians/Alaska Natives. The APCs for these groups were: Whites (−3.24%, 95% CI: −3.85 to −2.53), Blacks/African Americans (−4.73%, 95% CI: −5.32 to −4.15), Asians/Pacific Islanders (−5.21%, 95% CI: −6.05 to −4.46), and American Indians/Alaska Natives (−2.59%, 95% CI: −3.64 to −1.26). Among them, Blacks and Whites showed notable trends, especially the most recent trend of Blacks, which showed an increase in mortalities since 2015 (APC: 1.3%, 95% CI: −2.1 to 8.9). The data highlighted persistent racial disparities, with Blacks and American Indians exhibiting significantly higher mortality rates compared to other groups (Fig. 2). Supplementary Tables 3 and 4 (http://links.lww.com/MS9/A706) provide detailed AAMRs of different ethnicities, highlighting significant racial disparities.

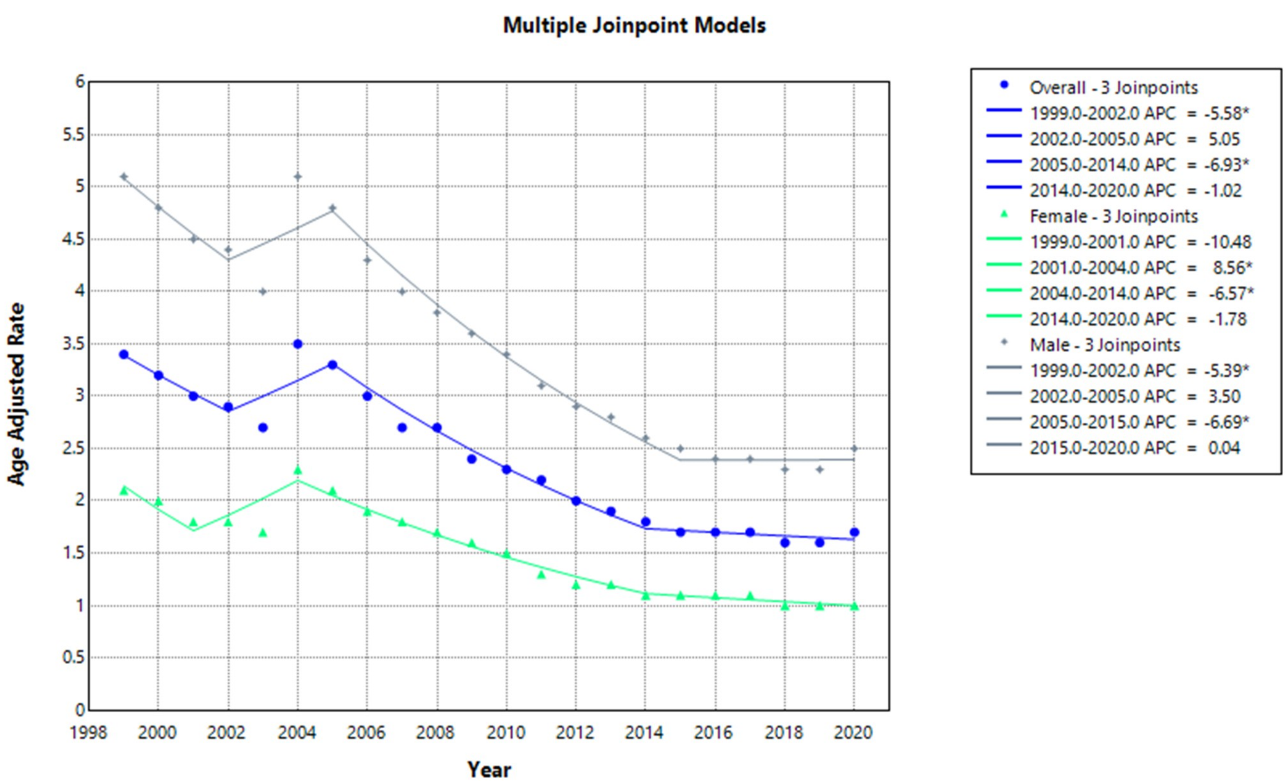

Figure 1. Overall and sex-stratified DCM-related AAMRs per 100 000 among population of the United States, 1999 to 2020. * Indicates that the APC significantly differs from zero at α = 0.05.

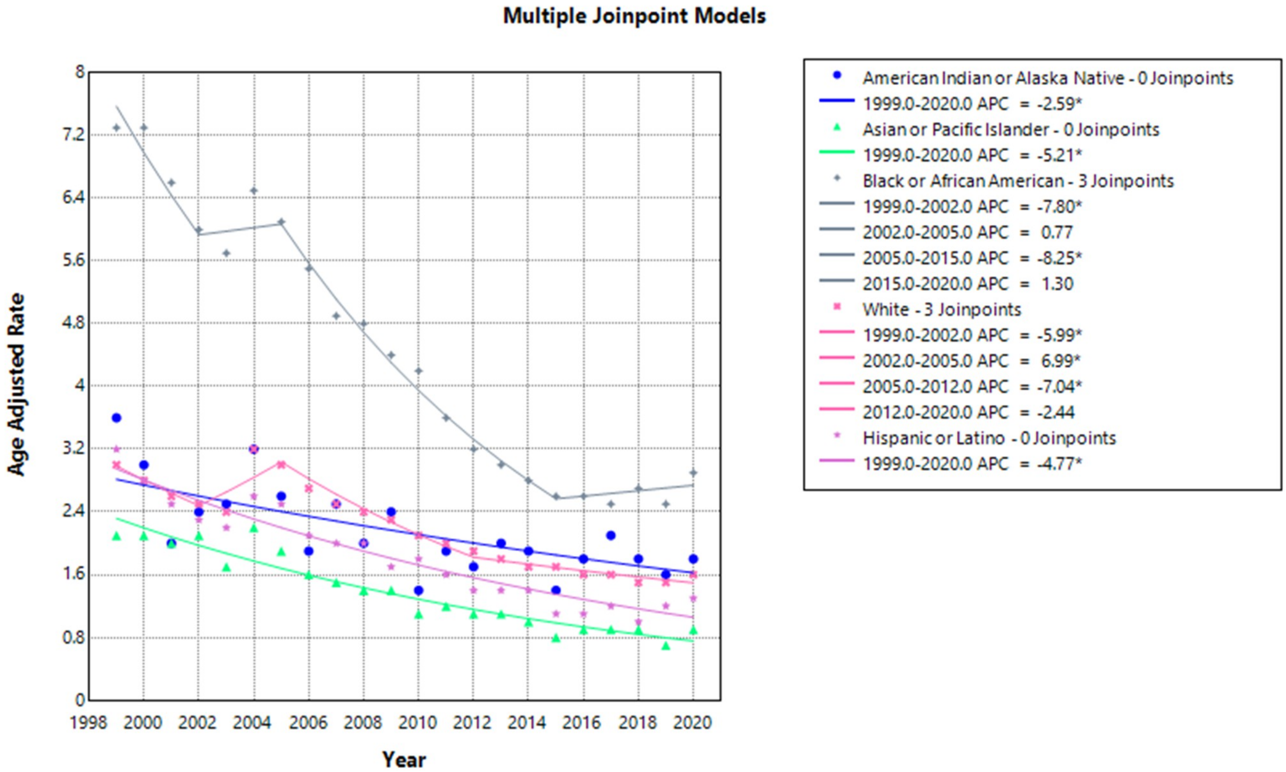

Figure 2. DCM-related AAMRs per 100 000 stratified by race in the United States, 1999 to 2020. * Indicates that the APC significantly differs from zero at α = 0.05.

Mortality trends by geographic region

Geographic analysis showed notable regional differences in DCM-related mortality. The highest reductions were observed in the Northeast (APC: −4.32%, 95% CI: −5.48 to −3.59), while the West experienced the slowest decline (APC: −2.97%, 95% CI: −3.35 to −2.56). The South and Midwest exhibited intermediate decline rates (Fig. 3). Trends and AAMRs over the years of study in census regions are included in Supplementary Tables 3 and 7 (http://links.lww.com/MS9/A706).

Mortality trends by state

The state-specific analysis revealed a wide variation in AAMRs across the United States. Hawaii had the highest AAMRs at 4.5, followed by Nevada at 4.2. Conversely, states such as Massachusetts, Vermont, and Nebraska had among the lowest AAMRs, ranging from 1.1 to 1.3. This geographic disparity highlights the influence of state-level healthcare infrastructure, access to specialized care, and public health policies in affecting DCM-related mortality rates (Fig. 4). Supplementary Table 4 (available at: http://links.lww.com/MS9/A706) provides detailed state-level AAMRs, highlighting significant geographic disparities.

Mortality trends by urbanization

The analysis also considered the status of urbanization and the place of death. Metropolitan areas experienced a more pronounced decline in AAMRs than non-metropolitan areas, indicating disparities in healthcare access and quality. Metropolitan areas showed an APC of −3.57% (95% CI: −4.26 to −2.86), whereas non-metropolitan areas exhibited an APC of −2.63% (95% CI: −3.73 to −1.72) (Fig. 5). Supplementary Tables 3 and 8 (http://links.lww.com/MS9/A706) provide detailed urbanization-related AAMRs and trends, highlighting significant disparities.

Discussion

This study revealed a significant decline in DCM-related mortality in the United States from 1999 to 2020, with an overall annual percent change (APC) of −3.43%. Despite this improvement, gender, racial, and geographic disparities persist. Males and Black or African American individuals exhibited disproportionately high mortality rates, while geographic analysis revealed slower mortality reductions in the West compared to the Northeast. Notably, the findings of this study indicate a significant decrease in DCM-related mortality in the United States over the past two decades, which may be attributed to advances in medical treatments, including the use of beta-blockers, ACE inhibitors, and implantable cardioverter defibrillators[10,11]. The widespread implementation of evidence-based guidelines and improved management strategies for heart failure may have contributed to these positive trends[12]. However, the persistent disparities observed across gender, racial, geographic, and state-level categories highlight ongoing inequities in healthcare access and outcomes[13]. We observed several key trends in this 20-year dilated cardiomyopathy (DCM) mortality data analysis. First,

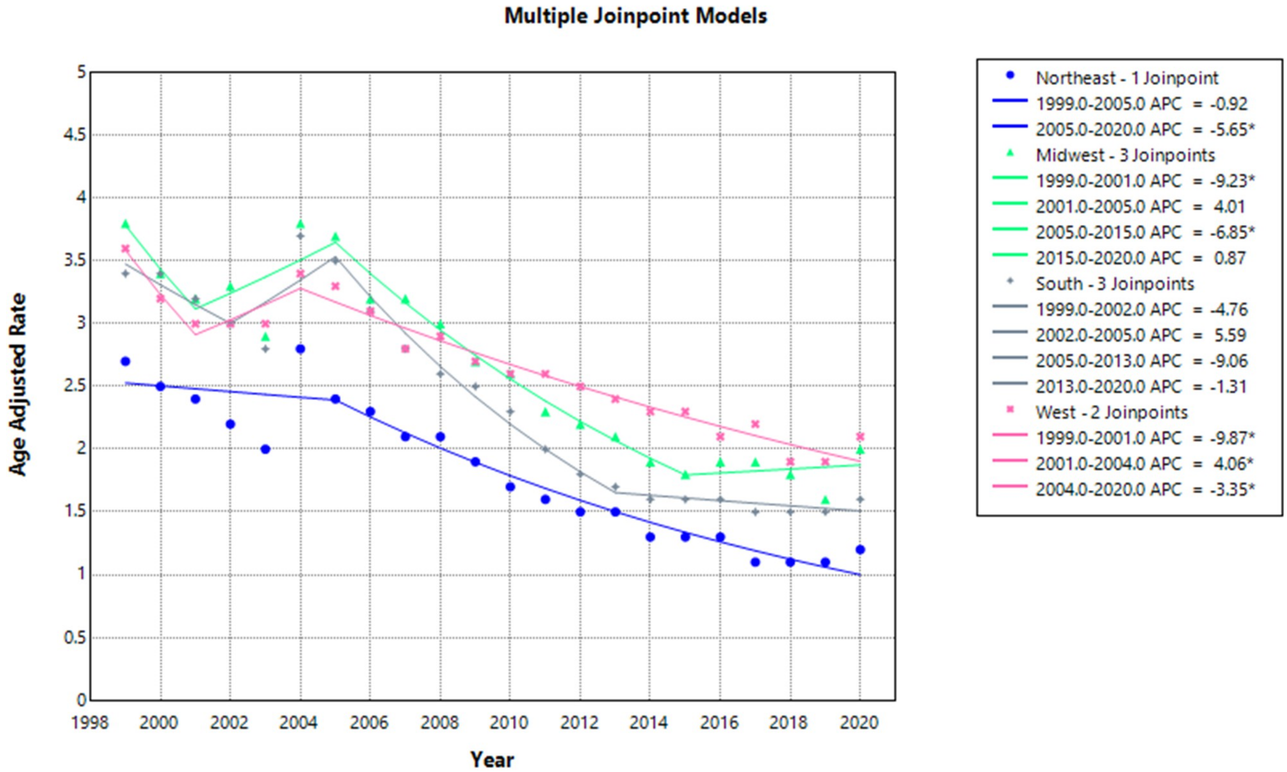

Figure 3. DCM-Related AAMRs per 100 000 stratified by census region in the United States, 1999 to 2020. * Indicates that the APC significantly differs from zero at α = 0.05.

DCM-related mortality saw an overall decline from 1999 to 2020. However, significant disparities persisted across gender, race, place of death, and geographic lines. Males accounted for 64.2% of DCM-related deaths, with higher AAMR compared to females. The racial analysis revealed that non-Hispanic Black individuals had the highest mortality rates, followed by Whites, with notable disparities in other ethnic groups (Table 1, Central Illustration).

Gender disparities revealed that while both males and females experienced declines in mortality, the magnitude and consistency of these trends varied[14]. Males generally experienced a slower reduction post-2014, potentially reflecting differences in healthcare-seeking behavior, comorbidities, or access to specialized care[15]. Scientific literature suggests that men are more likely to delay seeking medical help, which may contribute to slower mortality reduction[15]. Efforts to increase healthcare engagement among men, particularly in cardiovascular screening programs, could help reduce this gap. In contrast, females showed periods of increased risk, particularly from 2001 to 2004. The increase in mortality is maybe due to progression to diseases, possibly due to hormonal changes, increased incidence of comorbidities such as diabetes, and unequal access to cardiovascular care[16]. These findings suggest a need for more targeted preventive measures and improved healthcare delivery for both genders during critical periods. Racial disparities also persisted, particularly among Black and American Indian populations, emphasizing the need for improved healthcare access and targeted interventions for these groups[17]. Black individuals exhibited higher mortality rates throughout the study period, and while significant declines were observed, the reduction was less pronounced compared to other racial groups[17]. Factors such as socioeconomic status, access to healthcare, and the prevalence of comorbidities like hypertension and diabetes are known contributors to these disparities. Additionally, structural racism and historical mistrust of the healthcare system may play roles in limiting access to timely and effective care[18]. Targeted efforts to improve access to care, culturally sensitive healthcare practices, and addressing social determinants of health are essential to reduce these inequities. Geographic differences in mortality trends suggest that healthcare access, socioeconomic factors, and regional variations in treatment quality significantly impact outcomes[19]. The Northeast region showed the most substantial decline in mortality, suggesting the potential benefit of targeted healthcare interventions and regional healthcare quality[19]. Conversely, the slower decline in the West may indicate gaps in healthcare infrastructure or access that must be addressed. This contradicts previous studies, which show that the South has higher mortality rates in CVD patients[20]. This underscores the need for targeted intervention to improve the results nationwide. The analysis by the state showed considerable variation in DCM-related mortality rates, with some states demonstrating significantly higher AAMRs than others. States like Hawaii and Nevada had the highest AAMRs, which may reflect differences in healthcare access, socioeconomic conditions, and the availability of specialized cardiac care. In contrast, states with AAMRs, like Massachusetts, Vermont, and Nebraska, may benefit from better healthcare infrastructure, higher socioeconomic status, and greater access to preventive and specialized care. State-level studies that thoroughly analyze the causation of

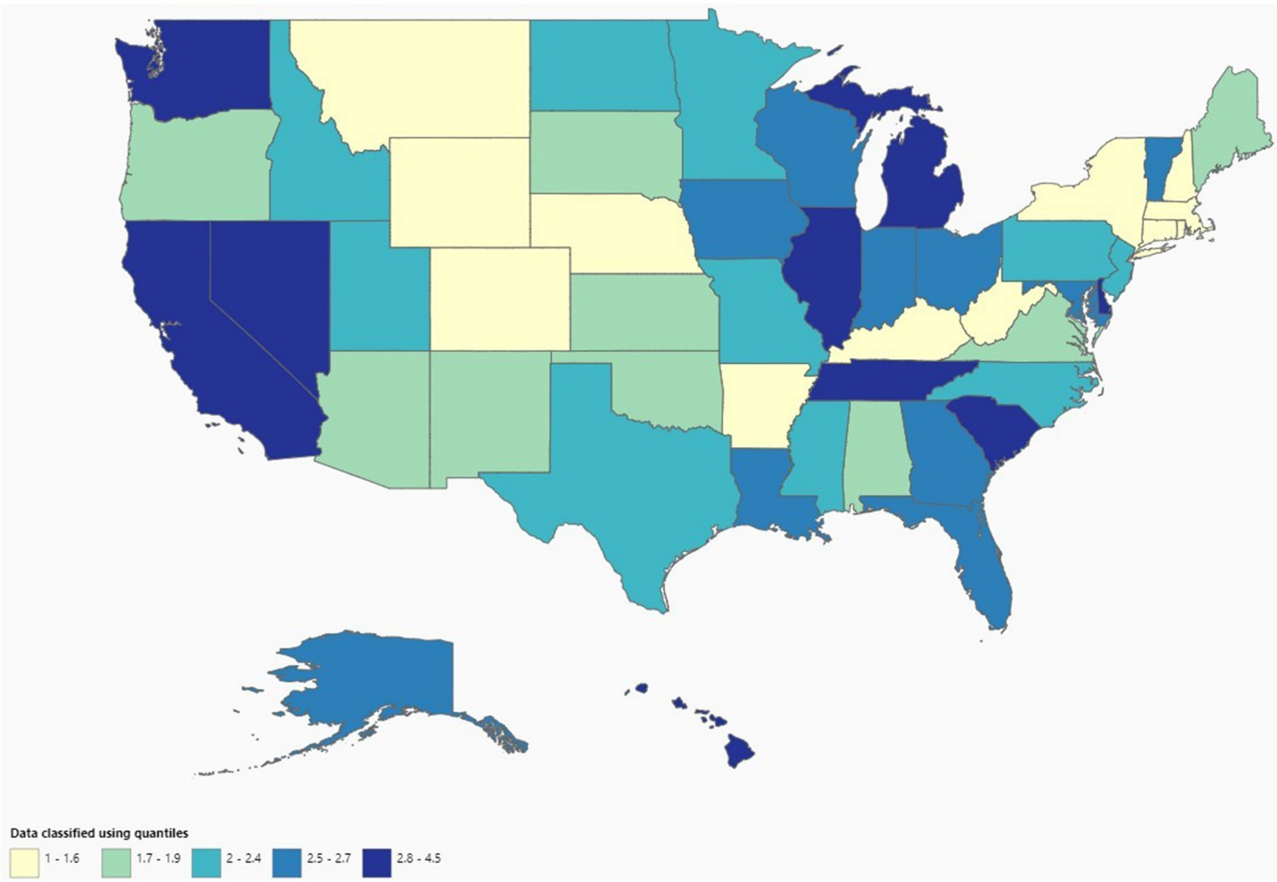

Figure 4. DCM-related AAMRs per 100 000 stratified by state among older adults in the United States, 1999 to 2020. Age-adjusted mortality rate per 100 000 among states (1–4.5).

disparities are needed. These findings highlight the need for state-specific public health initiatives that address local challenges, improve healthcare infrastructure, and ensure equitable access to care across all states. The differences in mortality trends between metropolitan and non-metropolitan areas further emphasize the importance of healthcare access. Urban areas, with better access to specialized care and advanced treatment options, showed more significant declines in mortality[21]. In contrast, non-metropolitan areas faced slower declines, underscoring the need for policies that enhance healthcare infrastructure in rural settings. Scientific studies indicate that non-metropolitan areas suffer from limited availability of advanced medical technologies, fewer healthcare professionals, and socioeconomic barriers that reduce access to care[22]. Telemedicine and mobile healthcare units could be potential solutions to bridge this gap and ensure equitable healthcare delivery[23]. Furthermore, Heart transplantation remains the definitive treatment option for DCM and advanced heart failure, offering the best long-term survival and functional capacity[6,24]. However, donor shortages limit its availability, with only about 2500 transplants performed annually in the US[6]. Left ventricular assist devices (LVADs) have emerged as a crucial alternative, revolutionizing advanced heart failure treatment[25]. LVADs significantly improve survival and quality of life for patients awaiting transplantation or ineligible[26]. Further implication of such new techniques and availability of these devices in locations, genders, and ethnicities at risk is needed to lower the mortality rates in DCM patients significantly.

Despite the overall reduction in DCM-related mortality, the persistent disparities based on gender, race, and geographic location underscore the need for targeted public health interventions. Expanding access to high-quality care in non-metropolitan areas and for racial minorities should be a priority. Additionally, the stagnation in mortality reduction post-2014 calls for renewed efforts in healthcare innovation, particularly for those who may be at greater risk of poor outcomes due to socioeconomic factors, limited healthcare access, or comorbidities.

Several limitations should be noted in this analysis. First, reliance on death certificates and ICD codes may result in misclassification of DCM as a cause of death, potentially underestimating or overestimating mortality trends. Second, the data lacks specific clinical details on treatment, comorbidities, or healthcare access, which could provide deeper insight into the observed trends. Third, socioeconomic factors, such as income or education, were unavailable in the database, limiting the ability to analyze how these factors may influence DCM mortality trends. Fourth, errors in the reporting of data, such as incorrectly identifying gender, race, and cause of mortality on death certificates, may distort the mortality data for American Indian/Alaska Natives and Asian/Pacific Islanders due to their relatively limited presence in national databases. Also, it is essential to note that the CDC WONDER database does not

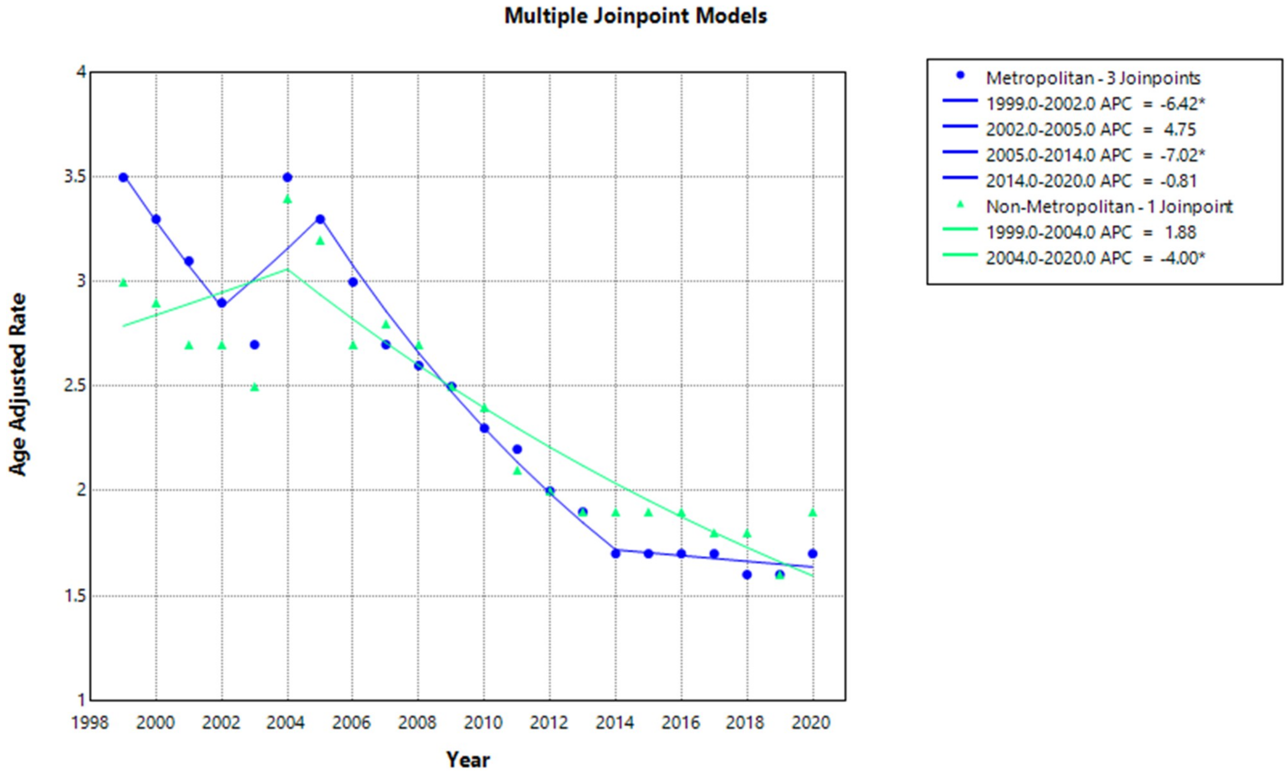

Figure 5. DCM-related AAMRs per 100 000 stratified by urbanization among older adults in the United States, 1999 to 2020. * Indicates that the APC significantly differs from zero at $\alpha = 0.05$.

provide incidence or prevalence, which is necessary for a specific implementation of public health. In addition, baseline characteristics such as atherosclerosis, atrial fibrillation, or a history of ischemic cardiomyopathy, which could contribute to mortality in DCM patients, could not be calculated.

Table 1

Number of overall deaths and aamr in different sets of populations

Variable	Dilated cardiomyopathy deaths (n)	AAMRs/CMRs (95% CI) per 1 00 000
Overall population	168 702 (100%)	2.3 (2.3-2.4)
Sex		
Male	108 390 (64.2%)	3.4 (3.4-3.4)
Female	60 312 (35.8%)	1.5 (1.5-1.5)
Census region		
Northeast	25 076 (14.8%)	1.8 (1.7-1.8)
Midwest	41 897 (24.8%)	2.6 (2.6-2.6)
South	60 409 (35.8%)	2.3 (2.3-2.3)
West	41 320 (24.4%)	2.6 (2.6-2.7)
Race/ethnicity		
American Indian or Alaska Native	1325 (0.7%)	2 (1.9-2.2)
Asian or Pacific Islander	3812 (2.2%)	1.2 (1.2-1.3)
Black or African American	32 503 (19.2%)	4.2 (4.1-4.2)
White	131 062 (77.6%)	2.1(2.1-2.1)
Hispanic or Latino	11 147 (6.6%)	1.7 (1.6-1.7)
Urbanization		
Metropolitan	140 233 (83.1%)	2.3 (2.3-2.3)
Nonmetropolitan	28 469 (16.8%)	2.3 (2.2-2.4)
Place of death		
Medical facility	81 941 (48.57%)	-
Decedent's home	56 548 (33.5%)	-
Hospice facility and nursing home	19 856 (11.7%)	-
Other	9818 (5.8%)	-

Conclusion

The overall decline in DCM-related mortality from 1999 to 2020 is encouraging. Still, the declining plateau in recent years highlights the ongoing need to address gender, racial, and regional disparities in outcomes. Future efforts should focus on increasing access to advanced therapies, particularly in underserved populations, and continuing research into novel treatment approaches to further reduce DCM mortality.

Ethical approval

Not applicable.

Consent

Informed consent was not required for this review.

Sources of funding

No funding was provided for research.

Author's contribution

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.

Conflict of interest

There was no conflict of interest among authors.

Research registration unique identifying number (UIN)

Not applicable.

Guarantor

Salih Abdella Yusuf.

Provenance and peer review

No it was not invited.

Data availability statement

The dataset supporting the conclusions of this article are included in this article.

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