Original article

SAGE Open Medicine

# Demographic and regional mortality trends in dilated cardiomyopathy in the United States; 1999–2020

SAGE Open Medicine
Volume 13: I-I1
© The Author(s) 2025
Article reuse guideline:
sagepub.com/journals-permissions
DOI: 10.1177/20503121251329806
journals.sagepub.com/home/smo



Syed Sarmad Javaid , Syed Usama Ashraf , Anoud Khan , Muntaha Irfan , Muhammad Usman Alamgir , Syed Daniyal Ahmed Jilanee , Hamiz Faisal , Muhammad Salman Peryani , Noor Ul Ain , and Ismail Khan ,

#### **Abstract**

**Background:** Dilated cardiomyopathy significantly impacts mortality and hospitalizations in the U.S., yet trends in dilated cardiomyopathy-related mortality are underreported. This retrospective study examines the trends in dilated cardiomyopathy-related mortality between 1999 and 2020.

**Methods:** The Centers for Disease Control and Prevention Wide-Ranging Online Data for Epidemiologic Research database was analyzed to study the trends in dilated cardiomyopathy-related mortality. Age-adjusted mortality rates per 100,000 people and annual percent changes with 95% Cls were determined. Joinpoint regression analysis was used to assess the trends in the overall demographic, geographic, and place-of-death variables.

Results: There were 168,702 dilated cardiomyopathy-related deaths reported between 1999 and 2020. The age-adjusted mortality rate declined from 3.40 in 1999 to 1.71 in 2020. Men unfailingly had a higher age-adjusted mortality rate than women. Non-Hispanic Black or African Americans had the highest age-adjusted mortality rate compared to other races, with a recent increase in annual percent change from 2015 to 2020. Hispanics, or Latinos, also showed an alarming rise in annual percent change of 11.10 from 2018 to 2020. Significant geographical variations were noted, with states in the top 90th percentile (Michigan, Washington, and Delaware) having approximately three times the age-adjusted mortality rate compared to states that fell in the lower 10th percentile.

**Conclusion:** Despite overall declines, racial and regional disparities persist, owing to the growing clinical burden. Targeted research and interventions are key to addressing disparities and reducing dilated cardiomyopathy-related mortality.

# **Keywords**

cardiomyopathy, dilated, United States, middle-aged, Black or African American

Received: 25 September 2024; accepted: 3 March 2025

# Introduction

Dilated cardiomyopathy (DCM) is an autosomal dominant disorder affecting 1 in 250 individuals, characterized by the enlargement and stretching of the heart's chambers, particularly the left ventricle (LV). DCM also encompasses various nongenetic etiologies, including infections, certain drugs, neuromuscular conditions, and pregnancy-related cardiomy-opathy. Annually, it leads to 10,000 deaths and 46,000 hospitalizations in the United States, making it a major contributor to cardiovascular mortality. The most common cause of DCM is idiopathic, a term used interchangeably for

## Corresponding author:

Anoud Khan, Ziauddin Medical College, Shahrah-e-Ghalib Road, Block 6 Clifton, Karachi 754600, Pakistan. Email: anoud.17451@zu.edu.pk

Creative Commons Non Commercial CC BY-NC: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 License (https://creativecommons.org/licenses/by-nc/4.0/) which permits non-commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access pages (https://us.sagepub.com/en-us/nam/open-access-at-sage).

Department of Medicine, University of Mississippi Medical Center, Jackson, MS, United States

<sup>&</sup>lt;sup>2</sup>Department of Medicine, Dow International Medical College, Karachi, SD, Pakistan

<sup>&</sup>lt;sup>3</sup>Ziauddin Medical College, Karachi, Pakistan

<sup>&</sup>lt;sup>4</sup>Liaquat National Medical College, Karachi, Pakistan

<sup>&</sup>lt;sup>5</sup>Rahbar Medical and Dental College, Lahore, PB, Pakistan

<sup>&</sup>lt;sup>6</sup>Agha Khan University Hospital, Karachi, SD, Pakistan

familial/genetic cases if no genetic link can be established.<sup>3</sup> A 2015 Global Burden of Disease study estimated a global prevalence of 2.5 million cases of cardiomyopathy, an increase of 27% since 2005.<sup>2</sup> In 2010, approximately 403,000 deaths were reported globally due to cardiomyopathy, underscoring its significant public health impact.<sup>2</sup>

Patients with idiopathic DCM ultimately require cardiac transplantation, the economic ramifications of which are extensive. A global report on DCM market insights, epidemiology, and market forecast states that the total prevalent cases of DCM in the United States (US) were 1,006,256 in 2017, which are expected to increase substantially by 2030. The projected rise in DCM cases is likely to be accompanied by a corresponding increase in DCM-related mortality. Therefore, it is vital to study mortality trends in DCM in mitigating the expected strain on U.S. healthcare and inform strategies for reducing mortality rates.

To date, there is a significant literature gap when studying mortality trends in DCM in the United States. Hence, this study aims to comprehensively analyze the trends in DCM-related mortality among demographic and geographic patterns from 1999 to 2020. By assessing these differences, the study aims to identify high-risk populations while encouraging them to get regular cardiovascular-related screenings. In addition to that, various cardiovascular health awareness programs and the allocation of resources in underserved areas of the country will also push to improve public health outcomes significantly.

#### **Methods**

# Study setting and data source

A retrospective analysis of DCM-related mortality was performed utilizing data obtained from the Centers for Disease Control and Prevention Wide-Ranging Online Data for Epidemiologic Research (CDC-WONDER). The total duration of the study comprises data collected between 1999 and 2020. DCM-related mortality from 1999 to 2020 was inspected using code I42.0 from the International Statistical Classification of Diseases and Related Health Problems-10th Revision (ICD-10). The same ICD codes were depicted previously to recognize DCM in administrative databases. 6 The multiple cause-ofdeath public-use record death certificates were examined to select DCM-related deaths, which were identified based on DCM reported as either contributing or underlying causes of death. This study was exempted from local institutional review board approval because it uses a de-identified government-issued public-use dataset and follows the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines for reporting.

#### Data abstraction

The records abstracted from the database used the I42.0 (ICD-10) code for DCM and were stratified by year, population size,

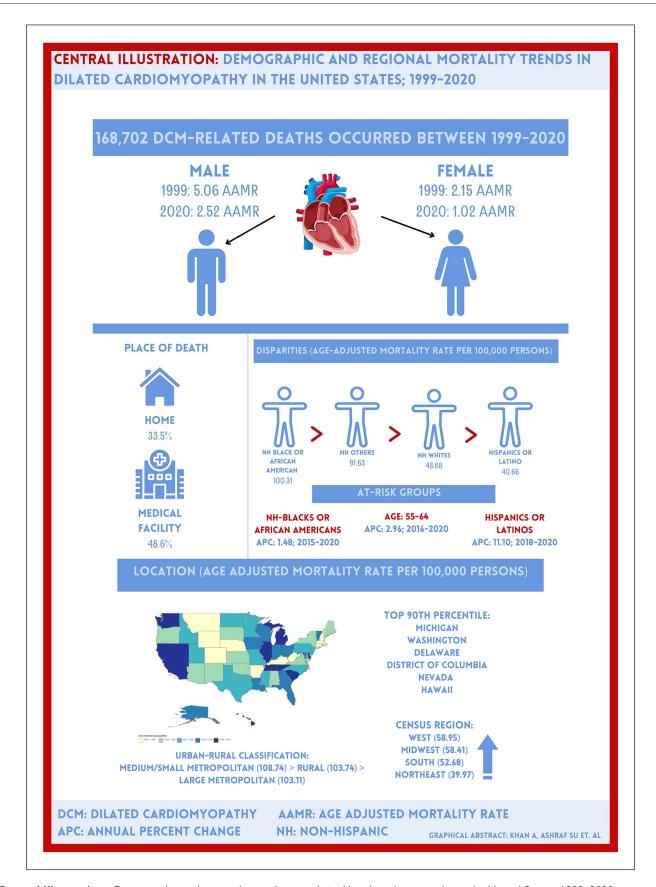
absolute number of deaths, gender, race/ethnicity, 10-year age groups, states, urban-rural status, census region, and place of death. The genders included were male and female as per the death certificates. Race/ethnicity included were categorized as Non-Hispanic Black or African American, Non-Hispanic White, Hispanic or Latino, Non-Hispanic Asian or Pacific Islander, and Non-Hispanic American Indian or Alaska Native. 10-year age groups were predetermined and abstracted by 25– 34, 35–44, 45–54, 65–74, 75–84, and >85 years. Place of death included for medical facilities fell into sub-categories (outpatient, emergency room, inpatient, death on arrival, or status unknown), home, hospice, and nursing home/long-term care facility. The exclusion criteria account for 540 deaths that were reported in the "not stated" category under race/ethnicity, mortalities occurring in 0–24 years when stratifying for age groups, and data on the "place of death" variable that was "missed" or "suppressed" by the CDC database. This information is dependent on the data reported on death certificates and has been used by prior analyses of the CDC-WONDER database. 7 The Urban-Rural population was defined by urban; large metropolitan area (population > 1 million), medium/small metropolitan area (population 50,000–999,999), and rural (population < 50,000) counties as per the 2013 U.S. census classification and in accordance to National Center for Health Statistics (NCHS) scheme.<sup>8</sup> According to the U.S. Census Bureau definitions; the census region was defined as Northeast, South, West, and Midwest.9

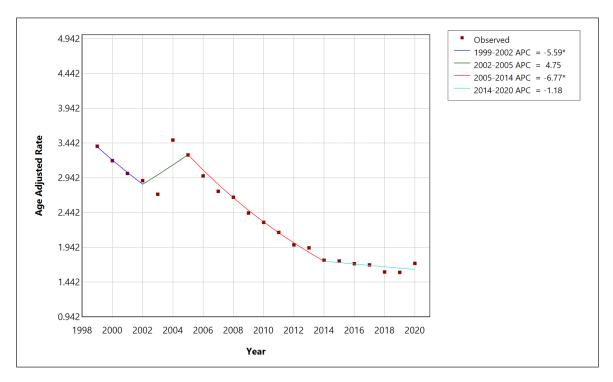
# Statistical analysis

Nationwide trends in DCM-related mortality were examined through crude-mortality rates (CMRs) and age-adjusted mortality rates (AAMRs), and were calculated per 100,000 population spanning from 1999 to 2020 by year, gender, race/ ethnicity, 10-year age group, place of death, state, urban-rural status, and census region with their respective 95% confidence intervals (CI). By dividing the number of DCM deaths by the resultant U.S. population of that year, CMR was obtained. DCM-related deaths were standardized to the year 2000 U.S. population to determine the AAMRs.<sup>9</sup> The Joinpoint Regression Program (Joinpoint V 5.0, National Cancer Institute; Produced by Statistical Research and Applications Branch, National Cancer Institute) was used to quantify the annual percent change (APC) with 95% CI in AAMR. 10,11 This software detects significant changes in AAMR over time by applying log-linear regression models to identify periods of temporal variation. APC trends were classified as increasing or decreasing if the slope of the regression line indicating mortality change was significantly different from zero, determined using 2-tailed t-tests. A p-value of less than 0.05 was considered statistically significant.

# Results

There were 168,702 DCM-related deaths reported between 1999 and 2020 (Central Illustration and Supplemental Table S1). Out of a total of 168,702 deaths, data on place of death





**Figure 1.** Dilated cardiomyopathy overall age-adjusted mortality rate in the United States, 1999–2020. All three Joinpoints. \*Annual Percent Change (APC) is significantly different from zero at the alpha = 0.05. Final selected model: three Joinpoints.

was accessible for 168,674 deaths. Of these, 48.6% of deaths occurred within medical facilities, 33.5% at home, 9.7% in nursing and long-term care, 5.8% in other locations, 2.1% in hospice, and 0.30% in unknown locations (Supplemental Table S2).

# Annual trends for DCM-related AAMR

The overall AAMR for DCM-related deaths was 3.40 in 1999 and 1.71 in 2020 (Supplemental Table S3). The trend of AAMR shows a general reduction in mortality from 1999 to 2002 (APC: -5.59; 95% CI: -8.83 to -2.24), preceded by an increase from 2002 to 2005 (APC: 4.75; 95% CI: -2.31 to 12.31). After this period, there was a progressive decrease in mortality until 2014 (APC: -6.77; 95% CI: -7.53 to -6.00). From 2014 to 2020, the decline in mortality slowed down (APC: -1.18; 95% CI: -2.60 to 0.26) (Figure 1).

# DCM-related AAMR stratified by gender

The majority of deaths occurred in males, with a total of 108,390 compared to 60,312 in females (Supplemental Table S1). In males, the AAMR was 5.06 in 1999 and 2.52 in 2020 (Supplemental Table S3). From 1999 to 2005, AAMR in males showed a decreasing trend, with an APC of -0.69 (95% CI: -2.81 to 3.43), after which there was a steeper decrease in AAMR (APC: -5.98; 95% CI: -10.47 to -5.12) until 2016, preceded by an increase in trend from 2016 to

2020 (APC: 0.81; 95% CI: -3.59 to 10.26). (Figure 2). In females, the AAMR was 2.15 in 1999 and 1.02 in 2020 (Supplemental Table S3). From 1999 to 2002, a downward trend was observed with an APC of -6.67 (95% CI: -14.09 to -1.33), followed by an upward trend (APC: 7.39, 95% CI: -0.66 to 11.38) until 2005. The AAMR then decreased until 2013 with an associated APC of -7.50 (95% CI: -12.70 to -5.91) and continued to decrease at a slower rate until 2020 with an APC of -2.28 (95% CI: -4.49 to 3.20) (Figure 2).

#### DCM-related AAMR stratified by race/ethnicity

Our results show that the absolute number of deaths from 1999 to 2020 was highest in NH-Whites (119,919), followed by NH-Black or African American (32,169), Hispanic or Latino (11,147), and 4927 in NH-American Indians or Alaskan natives and NH-Asians or Pacific Islanders combined (Supplemental Table S1). The AAMR from 1999 to 2020 is highest in NH-Black or African American (100.31), followed by NH-Whites (48.68), Hispanic or Latino (40.66), and others combined (91.63) (Supplemental Table S4).

NH-Black or African American had an AAMR of 7.35 in 1999 and 3.05 in 2020. The NH-Black or African American trend in mortality has been decreasing from 1999 to 2006 (APC: -3.28; 95% CI: -4.74 to -0.74), after which it fell at a faster rate between 2006 and 2015 with an APC of -8.31 (95% CI: -12.45 to -7.09) and then an upward trend after 2015–2020 with associated APC of 1.48 (95% CI: -1.93 to 8.53) (Supplemental Table S4, Figure 3).

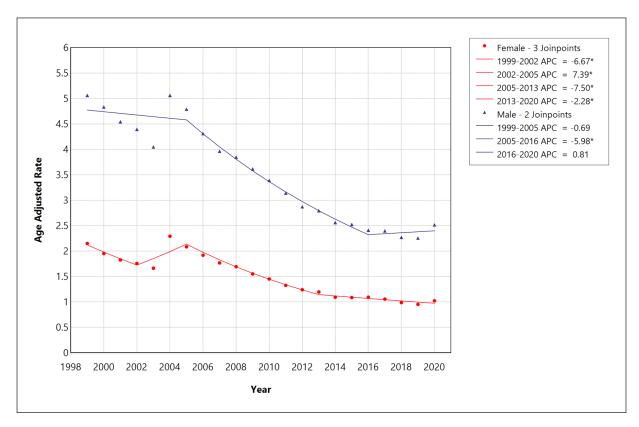


Figure 2. Dilated cardiomyopathy age-adjusted mortality rate stratified by gender in the United States; 1999–2020.

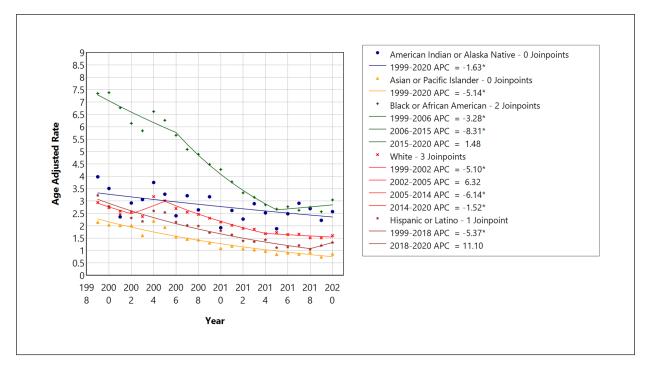


Figure 3. Dilated cardiomyopathy age-adjusted mortality rate stratified by race/ethnicity in the United States; 1999–2020.

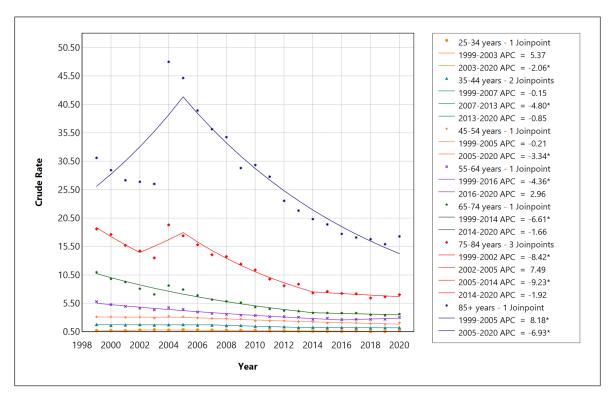


Figure 4. Dilated cardiomyopathy crude-mortality rate stratified by 10-year age groups in the United States; 1999–2020.

The NH-Whites had an AAMR of 2.94 in 1999 and 1.61 in 2020. Initially, we observed a drop in mortality trend from 1999 to 2002 (APC: -5.10; 95% CI: -12.09 to 0.51), preceded by an increasing trend from 2002 to 2005 (APC: 6.32; 95% CI: -6.20 to 10.14), followed by a decline from 2005 to 2014 (APC: -6.14; 95% CI: -10.75 to -4.17) and a slower rate of decline from 2014 to 2020 (APC: -1.52; 95% CI: -4.18 to 5.85) (Supplemental Table S4, Figure 3). Similarly, Hispanics or Latinos had an AAMR of 3.23 in 1999 and 1.33 in 2020. Initially, a downward trend in DCM-related mortality was observed from 1999 to 2018 (APC: -5.37, 95% CI: -8.10 to -4.47), followed by an upward trend from 2018 to 2020 with an APC of 11.10 (95% CI: -4.59 to 19.51) (Supplemental Table S4, Figure 3). Moreover, NH-American Indians, or Alaskan natives, and NH-Asian or Pacific Islanders both show a constant downward trend from 1999-2020, with an APC of -1.63 (95% CI: -2.91 to -0.18) and -5.14 (95% CI: -5.78 to -4.47), respectively (Supplemental Table S4, Figure 3).

# DCM-related CMR stratified by 10-year age groups

Individuals greater than 85 years had the highest CMR of 31.10 in 1999 and 17.27 in 2020. From 1999 to 2005 there was an upward trend in CMR (APC: 8.18; 95% CI: 3.17–19.68), followed by a downward trend from 2005 to 2020 (APC: -6.93; 95% CI: -8.71 to -5.64) (Supplemental Table S5, Figure 4).

Individuals aged 75–84 years had the second-highest CMR of 18.58 in 1999 and 7.03 in 2020. There was a decrease in CMR from 1999 to 2002 (APC: -8.42; 95% CI: -16.63 to -2.52), followed by an increase from 2002 to 2005 (APC: 7.49; 95% CI: -0.95 to 12.25). From 2005 to 2014 CMR fell at an APC of -9.23 (95% CI: -14.51 to -7.73) and fell further from 2014 to 2020 at an APC of -1.92 (95% CI: -5.44 to 7.12) (Supplemental Table S5, Figure 4).

Individuals aged 65–74 years had a CMR of 10.97 in 1999 and 3.60 in 2020, which resulted in a decline in CMR from 1999 to 2014 (APC: -6.61; 95% CI: -8.29 to -5.96), and from 2014 to 2020 (APC: -1.66; 95% CI: -4.69 to 7.30). Interestingly, individuals aged 55–64 years is the only age group with a rising trend from 2016 to 2020 (APC: 2.96; 95% CI: -1.74 to 11.89) (Supplemental Table S5, Figure 4).

Individuals aged 45–54 years had a CMR of 3.13 in 1999 and 2.09 in 2020. Decrease in CMR from 1999 to 2005, with an APC of –0.21; (95% CI: –1.83 to 4.46), and from 2005 to 2020 with an APC of –3.34; (95% CI: –4.29 to –2.90) (Supplemental Table S5, Figure 4).

Individuals aged 35–44 had a CMR of 1.78 in 1999 and 1.25 in 2020. From 1999 to 2007, there was a fall in CMR with an APC of -0.15 (95% CI: -1.23 to 1.54), and from 2007 to 2013, there was an APC of -4.80 (95% CI: -8.83 to -3.03). From 2013 to 2020, the rate of decline decreased to an APC of -0.85 (95% CI: -2.54 to 4.82). Moreover, individuals aged 25–34 years had a steady CMR of 0.69 in 1999 and 0.69 in 2020 (Supplemental Table S5, Figure 4).

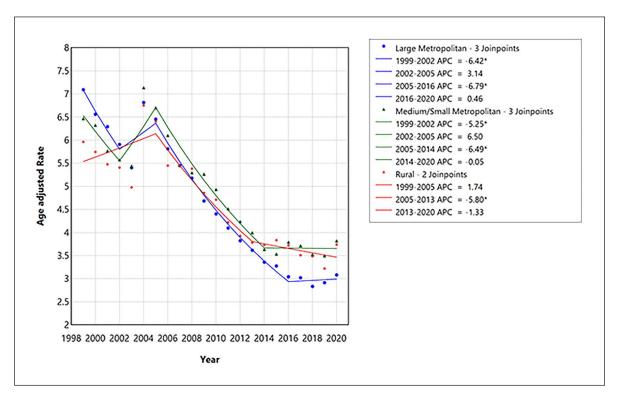


Figure 5. Dilated cardiomyopathy age-adjusted mortality rate stratified by urban-rural classification in the United States; 1999–2020.

# DCM-related AAMR stratified by geographic region

According to 2013 urbanization, the urban-rural classification revealed that rural areas and large metropolitan had comparable AAMR from 1999 to 2020; (103.74 and 103.11 respectively), and medium/small metropolitan had AAMR of 108.74. Large metropolitan showed a downward trend between 1999 and 2002 (APC: -6.42; 95% CI: -9.17 to -3.58), followed by a rise in trend from 2002 to 2005 (APC: -3.14; 95% CI: -2.96 to 9.62) preceded by a decline in AAMR till 2016 (APC: -6.79; 95% CI: -7.28 to -6.29). Between 2016 and 2020, there was an upward trend with an APC of 0.46 (95% CI: -1.91 to 2.89). (Supplemental Table S6, Figure 5).

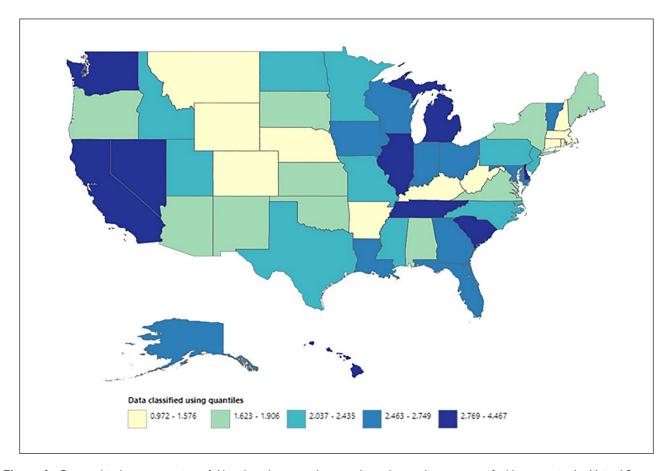
Rural areas had an upward trend in AAMR from 1999 to 2005 (APC: 1.74; 95% CI: -1.82 to 5.42), followed by a downward trend from 2005 to 2013 (APC: -5.80; 95% CI: -8.70 to -2.81) and a further decline from 2013 to 2020 (APC: -1.33; 95% CI: -4.76 to 2.23). Medium/small metropolitan had a downward mortality trend from 1999 to 2002 (APC: -5.25; 95% CI: -9.84 to -0.42), an upward trend from 2002 to 2005 (APC: 6.50; 95% CI: -3.26 to 17.24), and then a constant downward trend from 2005 to 2014 (APC: -6.49; 95% CI: -7.54 to -5.44). Followed by a slower decline in AAMR from 2014 to 2020 with an APC of -0.05 (95% CI: -1.96 to 1.89) (Supplemental Table S6, Figure 5).

Notable differences in AAMRs were observed in all of the United States. The AAMR varied from 0.97 in Kentucky to 4.47 in Hawaii. The top 90th percentile states were Michigan, Washington, Delaware, District of Columbia, Nevada, and Hawaii, having approximately three times the AAMR in comparison to states in the lower 10th percentile (Kentucky, Massachusetts, Colorado, Connecticut, Nebraska, and Montana) (Supplemental Table S7, Figure 6).

According to the census region, the West and Midwest had the highest overall AAMR (58.95 and 58.41, respectively), followed by the South (52.67) and Northeast (39.97). On average, the APC for the Northeast was -4.32 (95% CI: -5.56 to -3.08), the Midwest -2.90 (95% CI: -4.58 to -1.21), the South -3.48 (95% CI: -5.13 to -1.79), and the West -2.99 (95% CI: -4.97 to -0.97) (Supplemental Table S8, Online Figure 1).

## **Discussion**

To the best of our knowledge, this study is the first to offer a comprehensive analysis of DCM-related mortality stratified by demographic factors and regions across the United States from 1999 to 2020. Over this period, a total of 168,702 DCM-related deaths were reported. Initially, there was a drop in mortality rates from 1999 to 2002, followed by an increase from 2002 to 2005. Since 2005, the overall AAMR has steadily decreased. Moreover, males consistently had higher AAMRs compared to females and have shown a



**Figure 6.** Geographical representation of dilated cardiomyopathy age-adjusted mortality rate stratified by states in the United States, 1999–2020.

progressive increase in mortality since 2016. From 2016 to 2020, there has also been an increase in mortality among both males and females aged 55–64. Non-Hispanic Black or African American individuals have experienced an increasing AAMR since 2015, with the highest APC observed in Hispanic or Latino individuals from 2018 to 2020. Regional differences were also noted, with states in the top 90th percentile (Michigan, Washington, Delaware, the District of Columbia, Nevada, and Hawaii) having three times the AAMR compared to states in the lower 10th percentile. The West and Midwest regions, as well as non-metropolitan areas, exhibited the highest AAMRs.

Our findings highlight a promising decline in the overall AAMR of DCM from 1999 to 2020, owing to advancements in diagnosis and treatment modalities. The development of device therapies such as Implantable cardioverter defibrillators (ICDs) has proven to be a major milestone in reducing mortality by 23% in patients with ischemic and non-ischemic cardiomyopathy. Increased levels of Brain natriuretic peptide in patients of DCM can also guide risk stratification and therapies even before DCM becomes clinically evident. Use of integrated drug therapy with Angiotensin-converting enzyme inhibitors or Angiotensin receptor blockers, with

Beta-blockers alone or in conjunction with ICDs and Cardiac resynchronization therapy has been very beneficial in reducing all-cause mortality in patients of heart failure with reduced ejection fraction. <sup>14</sup> The current day knowledge on such various advancements (medical, diagnostic, and device therapies), and its widely accepted benefits also stand true for the diverse cohort of our study. Our study demonstrates a significant decline in mortality rates from 1999 to 2020, highlighting the impact of these advancements.

However, we noticed an increase in DCM-related mortality in men from 2016 to 2020. Males also had consistently higher AAMR than females throughout this study. This gender disparity is also evident in another study done on the incidence and prevalence of idiopathic DCM in Minnesota's Olmstead County; the age-adjusted ratio of female-to-male was 1:3. This heightened increase in disparity between males and females can be attributed to estrogen and testosterone, which work via estrogen and androgen receptors on cardiac tissue and can influence normal cardiac physiology. The Estradiol has been shown to counter the deleterious effects of reactive oxygen species that alter cardiac function, hence, females tend to experience cardiovascular events later in life as the estrogen levels decline after menopause. In contrast, evidence shows

that testosterone levels in cardiac tissue are significantly higher in males than in females. Higher levels of testosterone are associated with increased cardiac hypertrophy, especially LV, potentially exacerbating the risk of DCM. Another potential cause of male-to-female disparity can be credited to heavy alcohol consumption in males, which further increases the risk of acquired DCM. A ratio of 9:1 was reported for males as compared to females admitted for alcohol-induced cardiomyopathy. This discrepancy could result from differences in the amount of alcohol consumption, metabolism, and tolerance level between men and women. While treatment modalities and advancements have led to a reduction in overall mortality, lifestyle choices and biological factors continue to contribute toward higher mortality in males.

Our results also reflect an increase in mortality in patients 55-64 years of age from 2016 to 2020. This increase in the occurrence of DCM mortality among the middle-aged group can be attributed to a lack of cardiovascular screenings in middle-aged age groups. A study done to assess the role of cardiovascular screenings in first-degree relatives of DCM patients resulted in 14.1% of new cases diagnosed with DCM.<sup>17</sup> This percentage was higher in first-degree relatives aged 45-64 and among those with hypertension and obesity.<sup>17</sup> Cardiovascular screenings for DCM are encouraged for all age groups, including older adults >65, due to the possibility of developing DCM at later stages in life. 18 Also, other forms of heart diseases, hypertension, and diabetes have been among the most highly prevalent comorbidities in DCM in the United States. Sudden cardiac death makes up 30% of mortality in DCM.<sup>19</sup> Another probable cause is underutilized molecular genetic testing in cases of "idiopathic DCM"; a term that has been used interchangeably for familial/genetic DCM cases as well.6 One way by which genetic testing can be increased is to implement an intervention strategy in heart failure clinics that automates and streamlines genetic evaluation by pretesting genetic education and testing in patients who qualify as DCM.<sup>20</sup>

Significant differences between racial and ethnic groups resulted in NH- Black or African American having the highest and NH-Asian or Pacific Islander, having the lowest AAMR for DCM-related mortality. NH-Black or African American had increasing AAMR since 2015-2020, with the highest APC change observed as 11.10 in Hispanic or Latino from 2018 to 2020 when compared with other races/ethnicities. For ages, race and ethnic disparities have been a deep-seated crisis in the United States society. In particular, NH-Black or African Americans are at increased risk of incidence of DCM; with younger age at onset, their survival and outcomes related to DCM are much graver when compared to other races.<sup>21</sup> People suffering within the Black population are hardly likely to be referred for transplantation due to DCM, and they receive fewer referrals for effective evidence-based therapies.<sup>21</sup> The combined effects of neighborhood deprivation across different states are also detrimental for racial/ethnic minorities.21 Hispanics or Latinos have similar experiences. They are less likely to have health insurance among other races, have higher levels of poverty among recently immigrated individuals, especially after COVID-19, and have language barriers, all of which contribute to inequalities in acquiring access to health care. <sup>22,23</sup>

Furthermore, the non-metropolitans exhibited a higher mortality rate compared to metropolitan areas. This urban-rural variation in mortality is consistent with previous studies.<sup>23,24</sup> This can be attributed to the differences in socioeconomic status of rural and urban areas. During 1999-2019, AAMR rates of heart disease were reported to be 21% higher in 2019 in rural areas as compared to urban areas.<sup>25</sup> Lack of health insurance and financial resources and scarcity of primary care doctors and specialist cardiologists in rural areas also lead to health care imbalances for people needing care in rural areas.<sup>26</sup> Therefore, people living in rural areas often face greater public health challenges.<sup>25</sup> The consistent disparity between rural and urban regions calls for allocating health resources toward rural areas, and the development of policies, such as education and awareness about DCM among people of rural areas, can serve to strengthen the healthcare dynamics of rural regions.<sup>27</sup>

Similarly, there are significant disparities in mortality across states and census regions. In particular, the West and the Midwest regions of the United States display the highest AAMR, reflecting broader regional health disparities. Factors contributing to this increased mortality include the limited availability of specialist cardiac care and the wider challenges of healthcare access in rural and underserved communities, which are prevalent in these regions. Furthermore, these regions show substantial clustering of chronic disease prevalence, notably in Michigan and parts of the Pacific Northwest, which contributes to the elevated mortality. He disparity in mortality rates can also be related to the concentration of chronic disease prevalence and other cardiovascular conditions, which are more pronounced in these areas, amplifying the impact of DCM on overall mortality.

Lastly, this study also reports a considerable percentage of deaths occurring outside healthcare facilities, with 33.5% of deaths taking place at home versus 48.6% in a medical facility. Chuzi et al.<sup>30</sup> reports similar shifts in heart failure mortality at home that increased from 20.6% to 30.7% between 2003 and 2017. In addition, the average hospitalization expenses have also significantly increased from \$41,851 to \$53,941.50.31 This notable increase in hospitalization costs can be attributed to the growing number of DCM patients unable to afford treatment, which in turn is contributing to the increasing percentage of deaths at home. This discrepancy may also suggest that individuals who die at home could be receiving less intensive or delayed care or might not be presenting with advanced complications until later stages. Future research should focus on comparing quality care and outcomes between those managed at home and in medical facilities and evaluating whether early intervention strategies could improve patient outcomes and reduce overall healthcare costs.

## Limitations

There are several limitations in this study. Due to dependence on the ICD codes, DCM death certificate data may be misclassified. CDC-WONDER does not include information on patient diagnosis, type of treatment, and patients' socioeconomic factors. It also lacks important facts on patients' comorbidities, risk factors, lab tests, and genetic testing. In addition, a significant proportion of people died at home, and other unknown places; it is uncertain how the diagnosis of DCM was made. Some data was missing or suppressed in the hospice category and for people who died in unknown locations. When extracting for race/ethnicities, 540 deaths resulted in the "not stated" section. Hence they were not reported in the results. CDC-WONDER does not provide AAMRs, rather it provides crude rates when data is stratified by age groups or place of death. Lastly, due to the nature of this study being a retrospective analysis, the sample size for this study was predetermined at the time of abstracting DCM mortality data from the CDC-WONDER database, therefore the calculation and justification of the sample size cannot be established.

#### Conclusion

Overall, our study revealed a decreasing trend in DCM-related mortality within the U.S. population. In addition, we observed notable discrepancies in mortality rates when stratified by race, gender, and geographic region. To effectively address these disparities, significant efforts are necessary to ensure that quality healthcare is accessible to all individuals throughout the United States.

## **Acknowledgments**

All authors would like to extend their sincere regards to the team of the Research Council of Pakistan (RCOP) for their guidance and mentorship.

#### **ORCID iDs**

Syed Sarmad Javaid https://orcid.org/0000-0001-9304-7200
Syed Usama Ashraf https://orcid.org/0009-0000-8281-1189
Anoud Khan https://orcid.org/0009-0009-5913-7064
Muntaha Irfan https://orcid.org/0009-0000-6081-1567
Muhammad Usman Alamgir https://orcid.org/0000-0002-3880-9177

Hamiz Faisal https://orcid.org/0009-0005-6979-5205

Muhammad Salman Peryani https://orcid.org/0009-0006-9653-8578

Noor Ul Ain (b) https://orcid.org/0009-0003-9600-6617

#### **Statements and Declarations**

# Ethics approval

Ethical approval was not sought for the present study because: This study was exempt from local institutional review board approval because it uses de-identified government-issued public-use data set and follows the STROBE guidelines for reporting. "CDC-WONDER is a public service developed and operated by the

Centers for Disease Control and Prevention, an agency of the United States federal government. The public website at http://wonder.cdc.gov is in the public domain and only provides access to public-use data and information. You may access the information freely, and use, copy, distribute, or publish this information without additional or explicit permission."

#### Authors' contributions/CRediT

Syed Sarmad Javaid: supervision and project administration, manuscript review, and editing. Syed Usama Ashraf: concept of the study, data extraction, formal analysis, creating central illustration, manuscript writing, review, and editing. Anoud Khan: manuscript writing, review and editing, creating a central illustration. Muntaha Irfan: manuscript writing, review, and editing. Muhammad Usman Alamgir: data extraction, formal analysis. Syed Daniyal Ahmed Jilanee, Hamiz Faisal, Muhammad Salman Peryani, and Noor Ul Ain: manuscript writing. Ismail Khan: data extraction.

#### **Funding**

The author(s) received no financial support for the research, authorship, and/or publication of this article.

#### Conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

# Informed consent

Informed consent was not sought for the present study because: It uses a de-identified government-issued public-use dataset and follows the STROBE guidelines for reporting: The Public Health Service Act (42 U.S.C. 242m(d)) provides that the data collected by the NCHS may be used only for the purpose for which they were obtained; any effort to determine the identity of any reported cases, or to use the information for any purpose other than for statistical reporting and analysis, is against the law. Therefore users will:

\*Other Details\*:

- Use these data for statistical reporting and analysis only.
- Do not present or publish statistics representing nine or fewer births or deaths, including rates based on counts of nine or fewer births or deaths, in figures, graphs, maps, and tables.
- Make no attempt to learn the identity of any person or establishment included in these data.
- Make no disclosure or other use of the identity of any person or establishment discovered inadvertently and advise the Director, NCHS of any such discovery.

# Trial registration

Not applicable.

#### Data availability

The data presented in this article are available in the article and its online supplemental material.

#### Supplemental material

Supplemental material for this article is available online.

#### References

- Huggins GS, Kinnamon DD, Haas GJ, et al. Prevalence and cumulative risk of familial idiopathic dilated cardiomyopathy. *JAMA* 2022; 327(5): 454–463.
- 2. Schultheiss HP, Fairweather D, Caforio ALP, et al. Dilated cardiomyopathy. *Nat Rev Dis Prim* 2019; 5(1): 32.
- Mahmaljy H, Yelamanchili VS and Singhal M. Dilated cardiomyopathy. Treasure Island, FL: StatPearls Publishing, 2020
- Manolio TA, Baughman KL, Rodeheffer R, et al. Prevalence and etiology of idiopathic dilated cardiomyopathy (summary of a National Heart, Lung, and Blood Institute workshop. *Am J Cardiol* 1992; 69(17): 1458–1466.
- 5. Dilated Cardiomyopathy (DCM)—market insights epidemiology and market forecast—2030. Research and Markets, https://www.researchandmarkets.com/reports/5023872/dilated-cardiomyopathy-dcm-market-insights?utm\_source=dynamic&utm\_medium=GNOM&utm\_code=7213m8&utm\_campaign=1388096+-+Global+Dilated+Cardiomyopathy+(DCM)+Industry+(2017+to+2030)+-Hnsights%2c+Epidemiology+and+Market+Forecast&utm\_exec=jamu273gnomd#product-description (2020, accessed10 April 2024).
- Ababio Y, Kelly SP, Angeli FS, et al. Prevalence and clinical burden of idiopathic dilated cardiomyopathy in the United States. Am J Med Open 2023; 10: 100038.
- Centers for Disease Control and Prevention, National Center for Health Statistics. National Vital Statistics System, Mortality 1999–2020 on CDC WONDER Online Database, released in 2021. Data are from the multiple cause of death files, 1999– 2020, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program, 1990, http://wonder.cdc.gov/mcd-icd10.html (accessed 24 September 2023).
- Aggarwal R, Chiu N, Loccoh EC, et al. Rural-urban disparities: diabetes, hypertension, heart disease, and stroke mortality among Black and White adults, 1999–2018. *J Am Coll Cardiol* 2021; 77: 1480–1481.
- Ingram DD and Franco SJ. 2013 NCHS urban-rural classification scheme for counties. US Department of Health and Human Services, Centers for Disease Control and Prevention, Hyattsville: Maryland, 2014.
- Anderson RN and Rosenberg HM. Age standardization of death rates: implementation of the year 2000 standard. *Natl Vital Stat Rep* 1998; 47: 1–17.
- Joinpoint trend analysis software. Joinpoint regression program, version 5.0.Surveillance Research Program, National Cancer Institute, 1998, https://surveillance.cancer.gov/join-point/ (Accessed 25 September 2023).
- Santini M, Lavalle C and Ricci RP. Primary and secondary prevention of sudden cardiac death: who should get an ICD? *Heart* 2007; 93(11): 1478–1483.
- 13. Bozkurt B, Colvin M, Cook J, et al. Current diagnostic and treatment strategies for specific dilated cardiomyopathies: a scientific statement from the American Heart Association. *Circulation* 2016; 134(23): e579–e646.

 Tseng AS, Kunze KL, Lee JZ, et al. Efficacy of pharmacologic and cardiac implantable electronic device therapies in patients with heart failure and reduced ejection fraction. *Circ Arrhythm Electrophysiol* 2019; 12(6): e006951.

- Fairweather D, Cooper LT and Blauwet LA. Sex and gender differences in myocarditis and dilated cardiomyopathy. *Curr Probl Cardiol* 2013; 38(1): 7–46.
- Domínguez F, Adler E and García-Pavía P. Alcoholic cardiomyopathy: an update. Eur Heart J 2024; 45(26): 2294–2305.
- 17. Ni H, Jordan E, Kinnamon DD, et al. Screening for dilated cardiomyopathy in at-risk first-degree relatives. *J Am Coll Cardiol* 2023; 81(21): 2059–2071.
- Kaski JP and Cannie D. Clinical screening for dilated cardiomyopathy in at-risk first-degree relatives: who, when, and how? J Am Coll Cardiol 2023; 81(21): 2072–2074.
- Sen-Chowdhry S and McKenna WJ. Sudden death from genetic and acquired cardiomyopathies. *Circulation* 2012; 125(12): 1563–1576.
- Mohananey A, Tseng AS, Julakanti RR, et al. An intervention strategy to improve genetic testing for dilated cardiomyopathy in a heart failure clinic. *Genet Med* 2023; 25(3): 100341.
- Ntusi NAB and Sliwa K. Impact of racial and ethnic disparities on patients with dilated cardiomyopathy. *J Am Coll Cardiol* 2021; 78(25): 2580–2588.
- Hostetter M and Klein S. In focus: identifying and addressing health disparities among Hispanics | Commonwealth Fund, 2018. https://www.commonwealthfund.org/publications/2018/ dec/focus-identifying-and-addressing-health-disparitiesamong-hispanics (2018, accessed 20 October 2023).
- Funk C and Lopez MH. Hispanic Americans' experiences with health care. Pew Research Center Science & Society, https:// www.pewresearch.org/science/2022/06/14/hispanic-americansexperiences-with-health-care/ (2022, accessed 20 October 2023).
- 24. Manemann SM, St Sauver J, Henning-Smith C, et al. Rurality, death, and healthcare utilization in heart failure in the community. *J Am Heart Assoc* 2021; 10(4): e018026.
- Pierce JB, Shah NS, Petito LC, et al. Trends in heart failurerelated cardiovascular mortality in rural versus urban United States counties, 2011–2018: a cross-sectional study. *PLoS One* 2021; 16(3): e0246813.
- Curtin S and Spencer M. Key findings data from the National Vital Statistics System, https://www.cdc.gov/nchs/data/databriefs/db417.pdf (2021, accessed 20 October 2023).
- Coughlin SS, Clary C, Johnson JA, et al. Continuing challenges in rural health in the United States. *J Environ Health Sci* 2019; 5(2): 90–92.
- 28. Harrington RA, Califf RM, Balamurugan A, et al. Call to action: rural health: a presidential advisory from the American Heart Association and American Stroke Association. *Circulation* 2020; 141(10): e615–e644.
- Benavidez GA. Chronic disease prevalence in the US: sociodemographic and geographic variations by zip code tabulation area. *Prevent Chronic Dis* 2024; 21: 230267.
- Chuzi S, Molsberry R, Ogunseitan A, et al. Trends in place of death for cardiovascular mortality related to heart failure in the United States from 2003 to 2017. Circ Heart Fail 2020; 13(2): e006587.
- 31. Okorare O, Alugba G, Antia A, et al. National trends in racial disparities among hospitalizations and outcomes in patients with dilated cardiomyopathy. *J Cardiac Fail* 2024; 30(1): 196–196.