

Shifting Patterns of Out-Of-Hospital Mortality and Premature Life Loss in Cardiomyopathies: A Nationwide Population-Based Study

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Abstract

Background: Cardiomyopathies are a major cause of cardiovascular mortality, presenting age-dependent phenotypes ranging from sudden cardiac death (SCD) to progressive heart failure. Despite declining mortality rates, gaps in prevention and access to advanced therapies may manifest as shifts in the place of death and persistent premature mortality.

Objectives: To evaluate temporal trends in cardiomyopathy-related mortality in Brazil, assess age-related patterns in the place of death, and quantify premature mortality through years of life lost (YLL).

Methods: This nationwide, population-based ecological study analyzed 369,570 deaths in Brazil (1996–2024) in which cardiomyopathy (ICD-10 I42) was the underlying cause. Temporal trends were assessed using Poisson regression, and associations between age and place of death were evaluated using odds ratios (OR). The YLL were calculated using national life tables.

Results: Age-adjusted mortality declined by 1.7% annually ($p < 0.001$). Hospital deaths decreased from 75% to 43%, whereas home deaths increased from 20% to 38%, with a significant inflection point around 2011. Public roadway deaths, used as a proxy for SCD, were more frequent among adults aged 20–39 years (4.8%) than among those aged ≥ 60 years (0.8%; OR 2.88, 95% CI 2.68–3.10). Total YLL reached 6.83 million years. Individuals aged 20–39 years accounted for only 5.5% of deaths but contributed 12.8% of total YLL, averaging 42.9 years lost per death.

Conclusions: Despite declining mortality, out-of-hospital deaths have become more frequent. Excess YLL among young adults highlights gaps in SCD prevention. Age-tailored strategies are needed to reduce premature mortality.

Keywords: Cardiomyopathies; Mortality; Life Expectancy; Epidemiology.

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Introduction

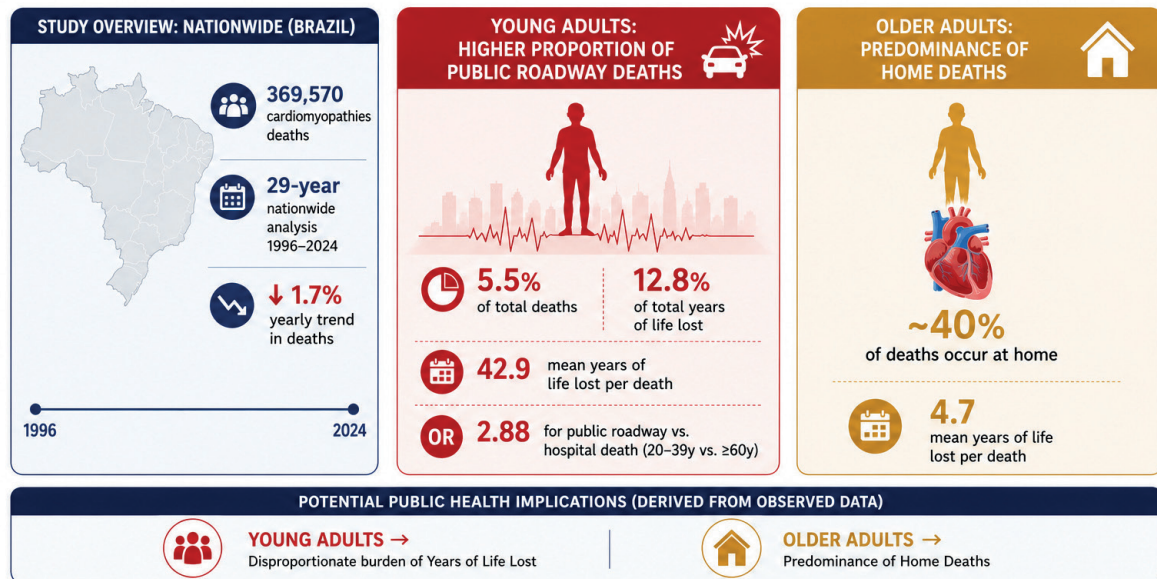
Cardiomyopathies represent a heterogeneous group of myocardial diseases characterized by mechanical and/or electrical dysfunction, frequently progressing to heart failure, life-threatening arrhythmias, and sudden cardiac death (SCD).¹ These conditions constitute a major cause of cardiovascular morbidity and mortality worldwide, with SCD emerging as a prominent complication, particularly

Central Illustration: Shifting Patterns of Out-Of-Hospital Mortality and Premature Life Loss in Cardiomyopathies: A Nationwide Population-Based Study

ABC Heart Failure & Cardiomyopathy

Shifting Patterns of Out-of-Hospital Mortality in Cardiomyopathies (Brazil, 1996–2024)

A 29-YEAR NATIONWIDE ANALYSIS



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Perazzo & Martins, et al. 2026. Source: Brazilian Mortality Information System (SIM/DATASUS) Years of Life Lost (YLL) using Global Burden of Disease reference life expectancy.

due to ventricular tachyarrhythmias in structurally abnormal hearts.² Despite therapeutic advances – including pharmacological, device-based, and interventional strategies – cardiomyopathies often culminate in end-stage disease, in which replacement therapies such as heart transplantation or mechanical circulatory support devices represent the final treatment option.³ The place of death may therefore reflect, in part, the failure to access these advanced therapies in a timely manner, especially in cases of rapid deterioration or sudden events.

Beyond the immediate cause of death, the location where death occurs carries important clinical and prognostic implications in cardiovascular diseases, including cardiomyopathies.^{4,5} In-hospital deaths often indicate access to advanced care, resuscitation efforts, and management of decompensated heart failure, whereas out-of-hospital deaths – whether at home or in public settings – frequently suggest abrupt arrhythmic events with limited opportunity for intervention. This distinction serves as a proxy for the acuity and mechanism of the terminal event, offering insights into disease progression, healthcare delivery, and potential preventability.^{4,5}

A key epidemiological feature of cardiomyopathies is the marked age-related divergence in clinical course. In younger patients, SCD often presents as the first symptomatic manifestation, triggered by malignant arrhythmias in

the setting of preserved systolic function, reflecting a predominantly electrical phenotype rather than pump failure.⁶ Conversely, older individuals typically follow a trajectory of progressive myocardial remodeling leading to refractory heart failure, with death resulting from gradual decompensation.⁷ This age-dependent pattern underscores distinct pathophysiological pathways – sudden arrhythmic death in the young versus protracted pump failure in the elderly – and highlights the disproportionate societal impact of premature mortality in younger cohorts.⁸

Although the burden of cardiomyopathies is well recognized, longitudinal studies comprehensively examining the place of death and its relationship with premature mortality remain limited.⁹ In particular, the use of YLL provides a critical metric that captures the “invisible burden” of disease – reflecting not only the number of deaths but also the profound loss of productive life years that crude mortality rates fail to convey.¹⁰ Few investigations have integrated long-term trends in terminal location with YLL quantification across diverse cardiomyopathic phenotypes.

The present study addresses these gaps by analyzing nearly three decades of national data on cardiomyopathy-related deaths, examining temporal shifts in place of occurrence, age-specific patterns consistent with sudden versus progressive modes of death, and the associated burden of premature mortality through YLL. By combining these

dimensions, this work aims to provide a population-level perspective on evolving patterns of cardiomyopathy mortality, informing strategies to improve timely access to life-saving therapies and reduce preventable loss of life.

Methods

This was an ecological, population-based, retrospective study using secondary mortality data from the Brazilian Mortality Information System (Sistema de Informações sobre Mortalidade – SIM), maintained by the Department of Informatics of the Unified Health System (DATASUS), Ministry of Health. All deaths with cardiomyopathy (ICD-10 code I42) recorded as the underlying cause were included, covering the entire Brazilian resident population from January 1, 1996, to December 31, 2024.

Data were obtained from predefined aggregated tabulations on the DATASUS platform, stratified by year of death, age group, sex, and place of death. These tabulations provide nationwide coverage of registered deaths and constitute the official source for mortality surveillance in Brazil. Analyses were based exclusively on fully aggregated and anonymized data, with no access to individual-level records.

The primary outcome was place of death, categorized as hospital, home, public roadway, other health establishment, other locations, or ignored/unknown. Explanatory variables included year of death (for temporal trend analysis), age group (standard categories: <1 year, 1–4, 5–9, 10–14, 15–19, 20–29, 30–39, 40–49, 50–59, 60–69, 70–79, ≥80 years, and ignored), and sex (male, female, ignored). For certain analyses, age groups were aggregated into broader categories (<20 years, 20–39 years, 40–59 years, and ≥60 years).

Statistical analyses were conducted using Python. Descriptive analyses calculated absolute and relative frequencies of place of death, stratified by age group and sex, with descriptive assessment of data completeness for key variables.

Temporal trends in the proportions of hospital and home deaths were evaluated using ordinary least squares linear regression. Structural changes were examined through segmented regression with the Chow test. Mortality rates were modeled using Poisson generalized linear models, incorporating mid-year population estimates from the Brazilian Institute of Geography and Statistics (IBGE) as a log-offset to derive annual percent changes and incidence rate ratios.

Associations between age group and place of death were assessed using chi-square tests of independence, with additional comparisons of proportions across strata performed using Z-tests. Odds ratios for home versus hospital death and public roadway versus hospital death, along with 95% confidence intervals, were calculated from contingency tables. An age-related gradient in home deaths was tested using linear regression, with age-group midpoints treated as a continuous predictor.

YLL were calculated by multiplying deaths in each age group by the remaining life expectancy from the 2020 Brazilian life table (IBGE), yielding both total and age-stratified estimates. Deaths occurring on public roadways were examined as a proxy for potential SCD, with proportions compared across age groups using chi-square and Z-tests, and odds ratios calculated relative to older strata. Age at death was incorporated through the calculation of YLL, which captures the burden of premature mortality and enables indirect age stratification of cardiomyopathy-related deaths.

Statistical significance was defined as a two-sided p-value <0.05, with 95% confidence intervals reported when applicable.

The study used publicly available, aggregated, and anonymized data without individual identifiers. Under Brazilian regulations, such analyses are exempt from research ethics committee review. This study follows the STROBE reporting guidelines for observational studies using routinely collected health data.

Results

Over the 29-year period (1996–2024), 369,570 deaths due to cardiomyopathies were registered in Brazil. Age-unadjusted mortality rates declined significantly by 1.7% annually (95% CI -1.8 to -1.6; $P<0.001$), confirming a sustained reduction in cardiomyopathy mortality after accounting for population growth, with a temporary disruption observed in 2020.

The proportion of hospital deaths decreased markedly from approximately 75% in 1996 to 43% in 2024, whereas home deaths nearly doubled, rising from 20% to 38%. A significant inflection point occurred around 2011, after which the shift toward out-of-hospital deaths accelerated.

Place of death varied substantially across age groups ($\chi^2 P<0.001$). Older individuals (≥60 years) exhibited the highest proportions of home deaths (approximately 40%), whereas younger age groups showed lower home-death rates and higher hospital-death rates (Table 1). A clear age-related gradient was observed, with the proportion of home deaths increasing progressively with advancing age.

Deaths occurring out of hospital were associated with a disproportionately higher burden of YLL, suggesting earlier age at death compared with in-hospital fatalities.

Deaths on public roadways, a proxy for potential SCD, were significantly more common among younger adults. Individuals aged 20–39 years had a 4.8% rate of public-roadway deaths compared with 0.8% among those aged ≥60 years (Table 1). Relative to individuals aged ≥60 years, the adjusted odds ratio for public-roadway versus hospital death was 2.88 (95% CI 2.68–3.10) for those aged 20–39 years and 1.95 (95% CI 1.85–2.06) for those aged 40–59 years (Table 2). The disproportion between the low contribution of younger individuals to total deaths and their high contribution to years of life lost (YLL), as well as the higher proportion of public-roadway deaths (a proxy for SCD) in younger age groups, is illustrated in Figure 1. These findings support distinct age-related phenotypes

Table 1 – Sociodemographic profile, place of death, and years of life lost due to cardiomyopathies in Brazil, between 1996 and 2024

Variable	Total Deaths (n)	% of Total	Hospital (%)	Home (%)	Public Road (%)	Total YLL (Years)	YLL per Death
Sex							
Male	210,654	57.0%	40.8%	38.2%	2.5%	4,950,368	23.5
Female	158,916	43.0%	45.2%	37.5%	0.9%	3,180,172	20.0
Age Group (Years)							
< 20	7,391	2.0%	76.4%	15.2%	2.1%	510,718	69.1
20–39 (Young Adults)	20,326	5.5%	54.2%	30.8%	4.8%	871,985	42.9
40–59 (Middle Age)	88,696	24.0%	48.9%	35.1%	3.2%	2,581,053	29.1
60–79 (Elderly)	162,610	44.0%	41.5%	39.4%	1.1%	3,740,030	23.0
≥ 80 (Very Elderly)	90,547	24.5%	36.8%	41.2%	0.4%	426,754	4.7

YLL: years of life lost.

of cardiomyopathy mortality, with a predominance of potentially preventable arrhythmic deaths among younger individuals and progressive pump failure among older adults (Central Figure).

The total burden of premature mortality was 6.83 million YLL. Although individuals aged 20–39 years accounted for only 5.5% of deaths, they contributed 12.8% of total YLL, with an average of 42.9 years lost per death – substantially higher than the 4.7 years lost per death among those aged ≥80 years (Table 1).

Discussion

This nationwide analysis spanning nearly three decades of cardiomyopathy-related mortality in Brazil reveals a paradoxical evolution characterized by a sustained decline in age-unadjusted mortality rates alongside a marked shift toward out-of-hospital deaths. The annual percent change of – 1.7% aligns with broader reductions in cardiovascular mortality observed in Brazil and other middle-income countries, largely attributed to improvements in diagnostic awareness, pharmacological therapy, and long-term management of cardiovascular risk factors.^{8–11} Similar trends have been reported across BRICS nations, although with slower declines than those seen in high-income regions, underscoring persistent structural and socioeconomic constraints.^{10,11}

Against this backdrop, the pronounced reduction in hospital deaths – from approximately 75% in the mid-1990s to 43% in 2024 – combined with the near doubling of home deaths and a clear inflection around 2011 mirrors international observations of shifting end-of-life care patterns in heart failure populations.⁰ While this transition may partly reflect the expansion of home-based or palliative care models, evidence from both high- and middle-income settings suggests that it may also indicate limited hospital capacity and barriers to accessing advanced care during terminal decompensation.^{12–14}

A defining characteristic of cardiomyopathy mortality is the strong age-dependent divergence in terminal phenotype, which is clearly reflected in the location of death. Among younger adults (20–39 years), the disproportionately high proportion of public-roadway deaths and an odds ratio of 2.88 compared with older individuals are consistent with a predominantly electrical phenotype marked by primary electrophysiological instability, although this interpretation cannot be directly confirmed by the present ecological data. Prior studies have consistently shown that SCD frequently represents the first clinical manifestation of cardiomyopathies in young individuals, often occurring in structurally less remodeled hearts and in the absence of advanced systolic dysfunction.^{1,6,7}

Hypertrophic cardiomyopathy and arrhythmogenic or genetic cardiomyopathies are particularly overrepresented in this context, with malignant ventricular arrhythmias constituting the dominant mechanism of death.^{1,7} The limited opportunity for resuscitation in out-of-hospital environments further amplifies lethality, as previously demonstrated in heart-failure cohorts in which SCD accounts for more than half of all out-of-hospital fatalities.¹⁵

Table 2 – Association between age and out-of-hospital death in cardiomyopathies

Age Group (Reference: ≥ 60 years)	Home vs. Hospital Death OR (95% CI)	Public Road vs. Hospital Death OR (95% CI)
< 20 years	0.45 (0.42–0.48)	0.95 (0.80–1.12)
20–39 years	0.82 (0.79–0.85)	2.88 (2.68–3.10)
40–59 years	0.91 (0.89–0.93)	1.95 (1.85–2.06)
≥ 60 years	1.00 (Ref.)	1.00 (Ref.)

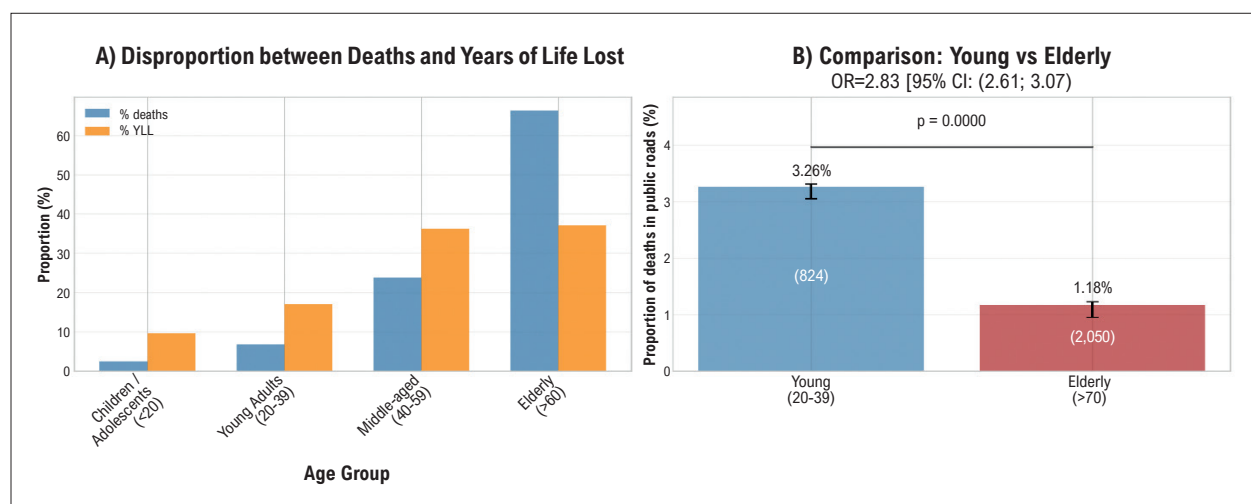


Figure 1 – Disproportionate burden and sudden death indicators in cardiomyopathies, Brazil, 1996–2024; (A) Proportion of total deaths and years of life lost (YLL) by age group, highlighting the disproportionate YLL among young adults; (B) Proportion of deaths occurring on public roads (a proxy for sudden death) in young (20–39 years) versus elderly (70+ years) patients.

Despite representing a small fraction of total deaths, young adults contributed disproportionately to premature mortality, with an average of 42.9 YLL per death. This finding aligns with Global Burden of Disease analyses showing that YLL heavily weight deaths occurring at younger ages and capture a substantial “invisible burden” not reflected in crude mortality counts.^{2,16–19} The magnitude of YLL observed in this subgroup reinforces the societal impact of sudden arrhythmic death and may suggest persistent gaps in primary prevention strategies. Robust evidence supports the efficacy of implantable cardioverter-defibrillators in reducing all-cause and sudden cardiac mortality in non-ischemic cardiomyopathy, particularly among younger patients and those with specific genetic or arrhythmogenic substrates.^{20,21} Nevertheless, the predominance of sudden out-of-hospital deaths in this age group suggests underutilization of familial screening, genetic risk stratification, and prophylactic device implantation, despite clear guideline support for these interventions.^{1,3,21}

In contrast, older individuals – particularly those aged ≥ 80 years – exhibited the highest proportion of home deaths, which may be compatible with a phenotype dominated by progressive myocardial remodeling and refractory pump failure. Longitudinal studies of dilated cardiomyopathy and chronic heart failure demonstrate that advancing age is associated with a shift from sudden to non-sudden modes of death, driven by progressive systolic dysfunction, comorbidity burden, and frailty.^{5,6} Along this trajectory, chronic low-output states culminate in gradual decompensation, frequently occurring outside hospital settings. Similar patterns have been observed in contemporary heart-failure cohorts, in which deaths at home or in hospice settings have increased over time while inpatient deaths have declined.^{12,13,15} The relatively low average YLL per death among the very elderly (4.7 years) underscores that the principal population-level burden of cardiomyopathies arises from premature mortality rather than deaths occurring at advanced ages.

The progressive shift toward out-of-hospital death may also raise concerns regarding potential barriers to accessing advanced cardiovascular therapies, although this could not be directly assessed with the available data. Heart transplantation remains the gold-standard treatment for eligible patients with end-stage cardiomyopathy, offering median survival exceeding a decade, whereas patients with stage D heart failure who lack access to advanced therapies face a median survival of less than two years.^{22,23}

Durable ventricular assist devices have similarly transformed outcomes, with one-year survival surpassing 80% in contemporary cohorts.^{22,23} However, both strategies depend on timely identification of advanced heart failure, early referral, and access to highly specialized centers. Multiple studies have highlighted that delayed recognition of advanced disease and fragmented referral pathways result in missed therapeutic windows, leaving many patients to deteriorate irreversibly at home or during interfacility transfer.^{24,25} In a continental-sized country with centralized transplant programs and pronounced regional and socioeconomic disparities, these barriers may be magnified, potentially contributing to terminal events occurring beyond the reach of life-prolonging interventions.

Taken together, the observed patterns may be compatible with complementary failures across the cardiomyopathy spectrum, although these interpretations remain hypothesis-generating given the ecological design of this study. Among older patients, the findings are consistent with a predominance of the pump-failure phenotype, and out-of-hospital deaths may reflect both appropriate end-of-life care and limited access to advanced therapies. Among younger individuals, the findings align with a predominance of electrical instability, with sudden cardiac arrest frequently occurring before diagnosis or initiation of protective strategies. While transplantation

and mechanical circulatory support primarily address terminal pump failure, ICD therapy represents a sentinel intervention capable of preventing catastrophic arrhythmic death in younger patients; yet the predominance of deaths occurring outside hospital settings indicates that this protective strategy remains insufficiently implemented at the population level.^{20,21}

Several limitations merit consideration. Reliance on ICD-10 code I42 may introduce misclassification, as cardiomyopathy encompasses heterogeneous etiologies with variable risk profiles, and regional variation in death-certification practices may bias cause-specific mortality estimates.^{26,27} Public-roadway deaths were used as a proxy for SCD and lack clinical or autopsy confirmation of arrhythmic mechanisms.^{7,15} Additionally, the transition to ICD-10 coding and the aggregated nature of mortality data limit etiological specificity and preclude individual-level adjustment for confounders.²⁸

Nonetheless, the strengths of this study include its nationwide coverage, extended temporal horizon, and integration of place of death with YLL, providing novel insight into the evolving epidemiology and age-specific burden of cardiomyopathies in a large middle-income country. Race/ethnicity data were not consistently available in the mortality database and were therefore not included in the primary analyses. This limitation may obscure important social and structural disparities in cardiomyopathy outcomes.

Conclusion

This nationwide, nearly three-decade analysis of cardiomyopathy-related mortality in Brazil demonstrates that improvements in overall survival have been accompanied by a clinically meaningful and epidemiologically revealing shift in the place of death. Although age-unadjusted mortality declined steadily – consistent with broader cardiovascular trends observed in Brazil and other middle-income countries – an increasing proportion of deaths now occur outside hospital settings. This divergence underscores that reductions in mortality alone are insufficient to characterize the quality, timeliness, and equity of care delivered across the cardiomyopathy spectrum.

Integrating place of death with YLL highlights two distinct, age-dependent phenotypes driving this burden. In younger individuals, the findings are compatible with a predominantly electrical phenotype, with sudden, out-of-hospital deaths accounting for a disproportionate share of premature mortality. The high YLL in this group reinforces the notion that SCD remains a leading and potentially preventable outcome, given the established efficacy of risk stratification, genetic screening, and implantable cardioverter-defibrillator therapy in high-risk cardiomyopathy populations.

Conversely, in the very elderly, the findings align with a predominance of progressive pump failure, frequently culminating in home deaths with comparatively low YLL – a pattern that may reflect either appropriate end-of-life care planning or constrained access to advanced therapies.

The growing predominance of out-of-hospital deaths across all ages may suggest systemic gaps in the continuum of care. For patients with advanced heart failure, this pattern may reflect delayed recognition and referral for transplantation or mechanical circulatory support—therapies that markedly improve survival but remain geographically concentrated and logistically inaccessible for much of the population. In younger patients, it may indicate persistent underuse of proven preventive strategies against malignant arrhythmias, with profound societal consequences measured in decades of life lost.

Taken together, these findings reposition cardiomyopathy mortality not merely as a question of how many patients die, but where, when, and at what stage of disease they do so. Place of death may serve as a pragmatic, population-level marker of missed opportunities – whether for life-saving interventions in younger individuals or timely advanced care in those with end-stage disease. Addressing this dual failure will require age-specific strategies: strengthening primary prevention and arrhythmic risk mitigation in younger individuals, while simultaneously improving early identification, referral pathways, and equitable access to advanced heart-failure therapies for older patients. Such an approach is essential to reduce premature mortality, optimize end-of-life care, and meaningfully lessen the long-term burden of cardiomyopathies in Brazil and comparable middle-income settings.

Author Contributions

Conception and design of the research, Acquisition of data, Analysis and interpretation of the data and Statistical analysis: Perazzo A, Martins GK, Nobre AP; Writing of the manuscript: Perazzo A, Martins GK, Nobre AP, Oliveira ALL, Araujo Junior JR, Montenegro GL,⁶ Montenegro CE,⁹ Montenegro P; Critical revision of the manuscript for intellectual content: Perazzo A, Martins GK, Nobre AP, Oliveira ALL, Araujo Junior JR, Montenegro GL,⁶ Montenegro CE,⁹ Montenegro P, Torres JH, Feijó F, Tenorio D, Sepulveda DPL, Steffen SP, Montenegro S, Gaiotto FA, Moraes F.

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Ethics Approval and Consent to Participate

This article does not contain any studies with human participants or animals performed by any of the authors.

Use of Artificial Intelligence

The authors did not use any artificial intelligence tools in the development of this work.

Availability of Research Data

The underlying content of the research text is contained within the manuscript.

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