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Economic burden and profile of early social security benefits for multiple sclerosis in Brazil, 2014-2023

Carga econômica e perfil de benefícios previdenciários precoces por esclerose múltipla no Brasil, 2014-2023

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ABSTRACT

Objective: To assess the economic burden of multiple sclerosis (MS) on the Brazilian social security system over a 10-year period (2014 to 2023). **Methods:** Early benefits (men: before 65 years; women: before 60-62 years) were analyzed and their distribution according to age, sex, and region of residence was described. The economic burden considered the quantity, duration (months), and costs (Brazilian Reais, BRL) associated with each type of benefit. The duration of long-term benefits (retirement and social assistance) was estimated by considering the average life expectancy in Brazil, with an adjustment for the excess mortality attributable to MS, and projected up to the end of the observation period and/or expected retirement age. Expenses were calculated by considering the duration and the number of minimum wages granted, adjusted for inflation through December 2023. **Results:** From 2014 to 2023, 16,149 MS-related benefits were granted in Brazil, of which 16,024 (99.2%) were early benefits (16,018 included in the economic burden analysis), with an average annual rate of 7.6 per million inhabitants. The average age at the time of benefit concession was 38.6±9.8 years. Among beneficiaries, 68.8% were women, 42.9% were employed, 19.8% self-employed, and 90.3% lived in urban areas. The total expenditure on MS-related benefits was BRL 657,247,720 during the period, with an accumulated duration of 23,717 years (284,612 months). **Conclusion:** Due to its disabling characteristics, MS is associated with early retirement and leaves during the prime productive years, with a burden over BRL 657 million in ten years.
Keywords: Multiple Sclerosis; Epidemiology, Descriptive; Social Security; Public Expenditures.

RESUMO

Objetivo: Avaliar a carga econômica da esclerose múltipla (EM) sobre o sistema previdenciário brasileiro em um período de 10 anos (2014 a 2023). **Métodos:** Foram analisados benefícios precoces (homens: antes de 65 anos; mulheres: antes de 60-62 anos) e caracterizada a distribuição dos benefícios quanto a idade, sexo e região de residência. A carga econômica considerou a quantidade, a duração (meses) e as despesas (R$) relacionadas a cada tipo de benefício. A duração de benefícios prolongados (aposentadoria e amparo social) foi estimada considerando a expectativa de vida média brasileira, com ajuste pelo excesso de mortalidade atribuível à EM, e projetada tendo como limite o período observado e/ou a idade esperada de aposentadoria. As despesas foram calculadas considerando a duração e o número de salários-mínimos concedidos, ajustados pela inflação até dezembro/2023. **Resultados:** De 2014 a 2023 foram concedidos 16.149 benefícios para EM no Brasil, sendo 16.024 (99,2%) precoces (16.018 incluídos na análise de carga econômica), com taxa média anual de 7,6 por milhão de habitantes. A média de idade no momento da concessão foi de 38,6±9,8 anos, sendo os beneficiários 68,8% mulheres, 42,9% empregados e 19,8% autônomos e 90,3% residentes em regiões urbanas. A despesa total com benefícios por EM foi de R$657.247.720 no período, com duração acumulada de 23.717 anos (284.612 meses). **Conclusão:** Por suas características incapacitantes, a EM associa-se a aposentadoria e afastamentos no auge da idade produtiva, gerando um ônus superior a R$657 milhões em 10 anos.
Palavras-chave: Esclerose Múltipla; Epidemiologia Descritiva; Previdência Social; Despesas Públicas.

Introduction

Multiple sclerosis (MS) is the most prevalent chronic inflammatory disease of the central nervous system (CNS). It affects more than 2 million people worldwide,[1,2] primarily young adults of productive age (20 to 50 years), with a higher prevalence among women (a 2:1 ratio compared to men). Geographically, the prevalence of MS ranges from 2 cases per 100,000 inhabitants in Asia to more than 100 per 100,000 inhabitants in North America and some European countries,[2] suggesting latitude as a risk factor and the influence of sunlight exposure, related to vitamin D levels.[1] In Brazil, the prevalence of multiple sclerosis has been the focus of several publications compiled in a systematic review that included 16 primary studies.[3] The estimated national average, resulting from a meta-analysis of these studies, was 8.69 per 100,000 inhabitants (95% CI: 5.99-12.60), ranging from 1.36 per 100,000 inhabitants in the Northeast (data from Recife) to 27.2 per 100,000 inhabitants in Rio Grande do Sul (data from Santa Maria; no data available for the Northern region).[3] Of note is the variability observed in studies conducted within the same state, such as in Rio de Janeiro, where four studies found prevalence rates ranging from 5 to 20 cases per 100,000 inhabitants.[3] Also noteworthy is the uneven distribution of magnetic resonance imaging (MRI) scanners, the main diagnostic tool for confirming the disease, across Brazil, ranging from 1.19 per 100,000 inhabitants in the Northeast to 2.78 per 100,000 inhabitants in the Central-West. This unequal access to MRI examinations may help explain the disparity in national prevalence rates.[4]

According to 2021 data from the Global Burden of Disease (GBD) study, the prevalence of MS in Brazil was 21.39 per 100,000 individuals of both sexes (95% uncertainty interval: 18.22-25.15), with 16.55 per 100,000 (13.92-19.53) among men and 25.70 (21.83-30.28) among women. By region, GBD estimated prevalence rates ranging from 14.43 per 100,000 in the North (12.01-17.24) to 39.21 (33.65-45.67) in the South of Brazil.[5]

The etiology of MS,[6] an incurable disease, involves both genetic and environmental factors. The interaction between these factors may explain the different clinical presentations of the disease,[7,8] which range from mild symptoms (that do not prompt medical attention) to severe and disabling manifestations, and are associated with distinct responses to available treatment strategies. In general, the disease manifests through relapses or acute attacks, which may resolve spontaneously or with corticosteroid therapy.[6] Early diagnosis and prompt referral are essential to minimize functional impairment and mitigate the significant impacts on quality of life and employability.[8] A Brazilian study involving 63 patients with MS (mean age 44.4 ± 10.7 years) reported that 7.9% were unemployed due to the disease, 15.9% were retired on disability, and 7.9% were on medical leave.[9] Among the 38 employed patients, 31% reported absences from work, 28% reported delays or early departures due to symptoms or treatments, and 50% had to adjust their professional activities to keep their jobs, adopting measures such as reduced working hours, remote work, or increased breaks.

In 2018, a study by the Brazilian Multiple Sclerosis Association (ABEM) evaluated the burden and cost of MS in Brazil from a societal perspective, focusing on productivity loss and work absenteeism.[10] Among the 694 participants (mean age 40.8 years), 38.7% were out of the labor market due to MS and 22.1% were retired on disability. Among 657 patients of working age, 11.5% took medical leave in the three months prior to the survey, and 22.7% were on leave for between 3 and 12 months. In that study, the average annual cost of productivity loss was R$6,517.00, calculated based on lost workdays in relation to the gross domestic product (GDP) per capita. Given the disabling effects of MS and its prevalence among individuals of productive age, the present study aimed to assess the economic burden of MS on the Brazilian social security system over a ten-year period (2014 to 2023).

Methods

A descriptive study was conducted using open data on benefits granted by the National Institute of Social Security (INSS), available on the Brazilian Open Data Portal of the Federal Government, covering the period from 2014 to 2023.[11] All types

of benefits (except pensions) granted over this ten-year period (2014-2023) to beneficiaries with MS were included, identified by the presence of the International Classification of Diseases (ICD) codes G35 and G35.0 in the records.

The analysis was restricted to early benefits, defined as any benefit granted before the minimum retirement age according to the legislation in force in each respective year, which was 65 years for men and 60 to 62 years for women (progressing from 2019 to 2023, in accordance with the transition rule established by Constitutional Amendment No. 103 of November 13, 2019[12]).

A sample size calculation was deemed unnecessary, given that all available data from the selected period were used, ensuring a comprehensive analysis of the studied population.

Variables

The variables available in the INSS databases, extracted from the Unified Benefit Information System (SUIBE), were used to characterize both the beneficiaries and the benefits. These included: benefit types, ICD (code), ICD-10 (name), date of birth, sex, clientele (rural or urban place of residence), type of affiliation (employment relationship), federative unit (state), number of minimum wages in the initial monthly income (RMI), month of concession, date of benefit authorization (DDB), date of benefit initiation (DIB), and date of benefit cessation (DCB).

The benefits were classified into three categories for analysis: Social assistance (social assistance benefit for persons with disabilities); Retirements (disability retirement due to general social security or due to work-related accident); Allowances (temporary disability benefit due to general social security or work-related accident).

The profile of benefits was characterized using demographic and occupational data, including age in years and age-group classification (5-year intervals), sex, and place of residence.

The economic burden was estimated based on the number (count of benefits granted by category), duration of benefits, and the number of minimum wages in the RMI, which together comprised the cost components.

Data Analysis

The analyses were conducted descriptively, considering absolute and relative frequencies for categorical variables (types of benefits, sex, clientele, type of affiliation, state, and economic sector) and means/medians with measures of dispersion for quantitative variables (age, number of minimum wages, benefit duration, and expenses). The number of benefits was also calculated and presented as an average annual rate per million inhabitants, taking into account the distribution of benefits by federative unit (state) and at the national level, adjusted for population distribution by age and sex for each year.[13]

The duration of benefits was calculated based on the interval (in months) between the date of benefit initiation (DIB) and the date of benefit cessation (DCB). Records showing inconsistencies (DIB later than DCB) were excluded from the economic burden analysis. In the absence of DIB information, the month of concession was used (applying the first day of the month). When DCB data were missing, projections were made according to the type of benefit: a) for temporary disability benefits, a maximum initial concession period of 120 days was assumed, as established by Law No. 13.457/2017;[14] or b) for long-term benefits, such as retirement and social assistance, duration was projected up to either the end of the observed period (December 2023) or the expected retirement age by sex (65 years for men and 60-62 years for women, according to current regulations).

Furthermore, the projection was adjusted for population mortality, by age and sex,[15] and corrected for excess mortality attributable to MS (hazard ratio, HR: 1.75; 95% CI: 1.07-2.87).[16] The expenses were calculated based on benefit duration and number of minimum wages granted, applying the value of the minimum wage for each year, in Brazilian reais (R$), adjusted for inflation using the National Broad Consumer Price Index (IPCA) up to December 2023. For benefits with DIB dates prior to January 2014 but

granted between 2014 and 2023, the 2014 minimum wage value was applied for the preceding years.

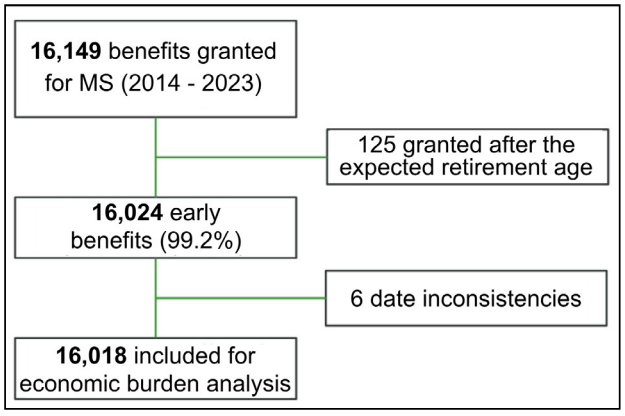
Ethical Aspects

The study used open data that contains no identifying information regarding beneficiaries or workplaces. Therefore, approval by a Research Ethics Committee was not required, in accordance with Resolution No. 510 of the National Health Council, 2016.[17]

Results

During the analysis period, 16,149 benefits related to MS were identified in Brazil, of which 16,024 were granted prematurely (99.2%) and were included in the benefit profile analysis. For the economic burden analysis, six records were excluded due to date inconsistencies, resulting in 16,018 valid records (Figure 1).

Figure 1. Flowchart of Data Selection for Analysis



Profile of Benefits

The characteristics of the beneficiaries are presented in Table 1. Of the total benefits, 68.8% were granted to women, 42.9% to individuals with formal employment, and 19.8% to self-employed workers. Additionally, 90.3% of the benefits were granted to residents of urban areas. The average age at the time of benefit concession was 38.6 ± 9.8 years.

Allowances represented the largest share of benefits (11,682; 72.9%), followed by retirements (3,175; 19.8%) and social assistance benefits (1,167; 7.3%). However, the beneficiary profile varied according to the type of benefit analyzed. Retirements were granted to individuals who were, on average, five years older than those who received social assistance or allowances. Nonetheless, in this sample, retirement benefits were granted approximately 19 years before the minimum age required for retirement by age.

While the majority of allowances (48.2%) and retirements (39.0%) were granted to employed individuals, social assistance benefits were mostly granted to unemployed persons (65.7%). Although most beneficiaries resided in the South and Southeast regions, social assistance benefits showed a slightly higher concentration in the North and Northeast regions (Table 1).

The average annual rate of benefits granted in Brazil was 7.6 benefits per million inhabitants, with substantial variation across the national territory. As shown in Figure 2, the benefits were concentrated in the states of the South and Southeast regions, as well as in the Federal District, which exhibited the highest rate (19.25 per million inhabitants).

In total, the accumulated duration of MS-related benefits in the period from 2014 to 2023 amounted to 23,717 years (284,612 months). The total expenditure for this period was R$657,247,721 (Figure 3).

Early retirements were the category that contributed the most to both total accumulated duration (66%) and total expenditure (74%) (Figure 3). Retirements also showed the highest medians for both duration and expenditure per beneficiary (Table 2).

In contrast, temporary disability benefits (allowances) had the shortest duration and lowest expenditure per beneficiary (Table 2); however, their cumulative total expenditure was substantially higher than that of social assistance benefits (Figure 3), owing to the large number of allowances granted during the study period.

Table 1. Characteristics of Beneficiaries by Type of

Granted Benefit

Characteristic		Social Assistance	Retirement	Disability Benefit	Total
Total n (%)		1.167 (7.3)	3.175 (19.8)	11.682 (72.9)	16.024
Sex	Female	821 (70.4)	2.077 (65.4)	8.124 (69.5)	11.022 (68.8)
	Male	346 (29.6)	1.098 (34.6)	3.558 (30.5)	5.002 (31.2)
Age, years	Mean (SD)	37.1 (13.0)	42.5 (8.9)	37.6 (9.4)	38.6 (9.8)
	Median(IQR)	37.3 (26.7 a 47.4)	42.2 (35.7 a 49.3)	37.0 (30.5 a 44.1)	38.1 (31.3 a 45.6)
Age group	05-09	9 (0.8)	0 (0.0)	0 (0.0)	9 (0.1)
	10-14	27 (2.3)	0 (0.0)	0 (0.0)	27 (0.2)
	15-19	87 (7.5)	0 (0.0)	60 (0.5)	147 (0.9)
	20-24	115 (9.9)	38 (1.2)	798 (6.8)	951 (5.9)
	25-29	125 (10.7)	180 (5.7)	1.662 (14.2)	1.967 (12.3)
	30-34	133 (11.4)	435 (13.7)	2.224 (19.0)	2.792 (17.4)
	35-39	146 (12.5)	603 (19.0)	2.180 (18.7)	2.929 (18.3)
	40-44	134 (11.5)	614 (19.3)	1.962 (16.8)	2.710 (16.9)
	45-49	167 (14.3)	537 (16.9)	1.378 (11.8)	2.082 (13.0)
	50-54	113 (9.7)	434 (13.7)	840 (7.2)	1.387 (8.7)
	55-59	79 (6.8)	264 (8.3)	457 (3.9)	800 (5.0)
	60-64	31 (2.7)	68 (2.1)	117 (1.0)	216 (1.3)
	65-69	1 (0.1)	2 (0.1)	4 (0.0)	7 (0.0)
Client Type	Rural	15 (1.3)	142 (4.5)	295 (2.5)	452 (2.8)
	Urban	1.102 (94.4)	2.722 (85.7)	10.644 (91.1)	14.468 (90.3)
	(Missing)	50 (4.3)	311 (9.8)	743 (6.4)	1.104 (6.9)
Type of Affiliation	Self-employed	223 (19.1)	659 (20.8)	2.285 (19.6)	3.167 (19.8)
	Unemployed	767 (65.7)	909 (28.6)	2.890 (24.7)	4.566 (28.5)
	Domestic worker	52 (4.5)	70 (2.2)	208 (1.8)	330 (2.1)
	Employee	0 (0.0)	1.237 (39.0)	5.636 (48.2)	6.873 (42.9)
	Employer	4 (0.3)	0 (0.0)	0 (0.0)	4 (0.0)
	Equivalent to self-employed	1 (0.1)	0 (0.0)	0 (0.0)	1 (0.0)
	Voluntary contributor	106 (9.1)	138 (4.3)	359 (3.1)	603 (3.8)
	Opting for Law 6.184/74	0 (0.0)	9 (0.3)	2 (0.0)	11 (0.1)
	Special insured	13 (1.1)	151 (4.8)	301 (2.6)	465 (2.9)
	Special insured Casual worker	1 (0.1)	2 (0.1)	1 (0.0)	4 (0.0)
Region	Central-West	135 (11.6)	184 (5.8)	970 (8.3)	1.289 (8.0)
	North	58 (5.0)	58 (1.8)	199 (1.7)	315 (2.0)
	Northeast	237 (20.3)	412 (13.0)	1.293 (11.1)	1.942 (12.1)
	South	154 (13.2)	721 (22.7)	2565 (22.0)	3.440 (21.5)
	Southeast	583 (50.0)	1.800 (56.7)	6.655 (57.0)	9.038 (56.4)

SD - Standard Deviation; IQR - Interquartile Range.

Figure 2. Average Annual Rate of Benefits Granted per Million Inhabitants in Brazil bay Federative Unit

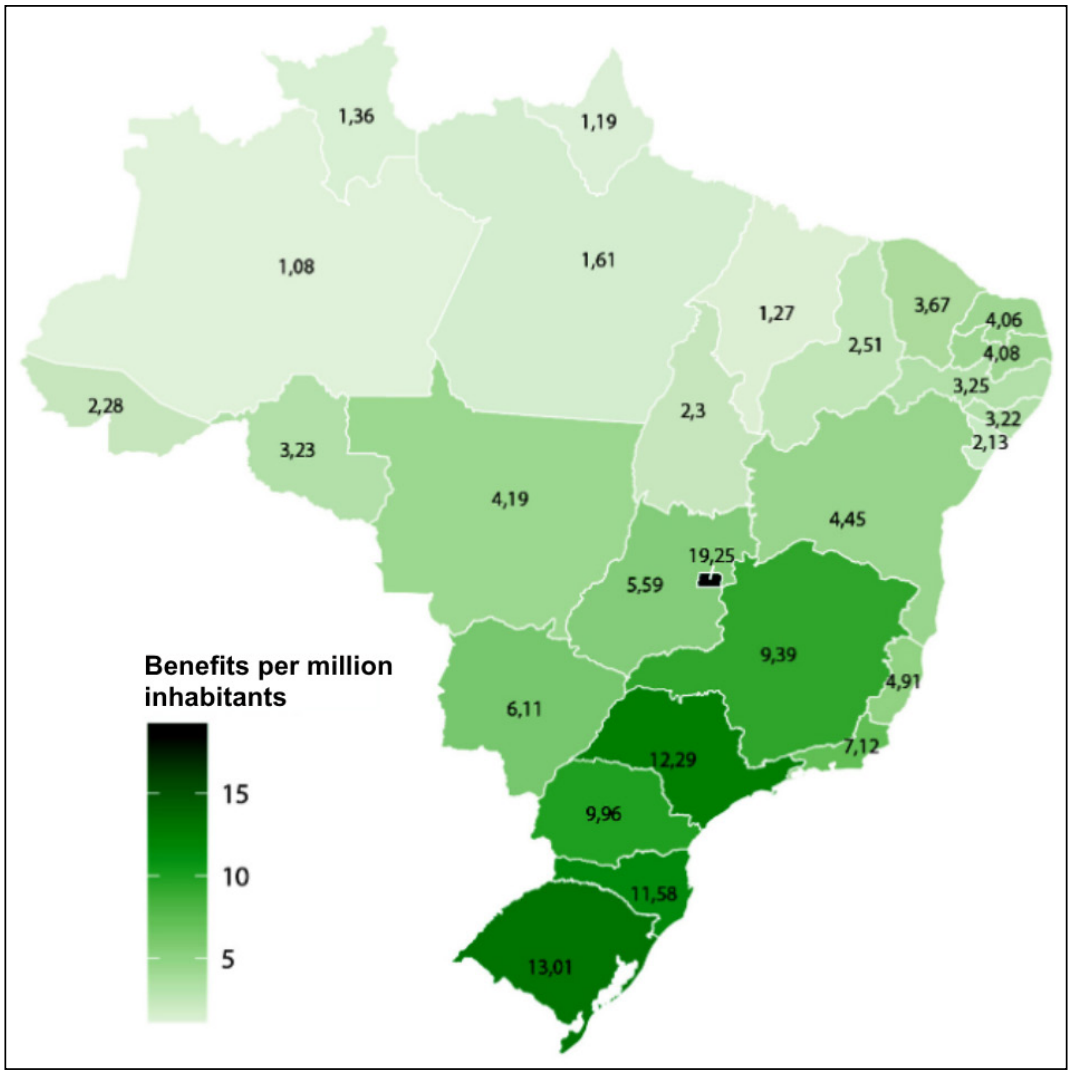
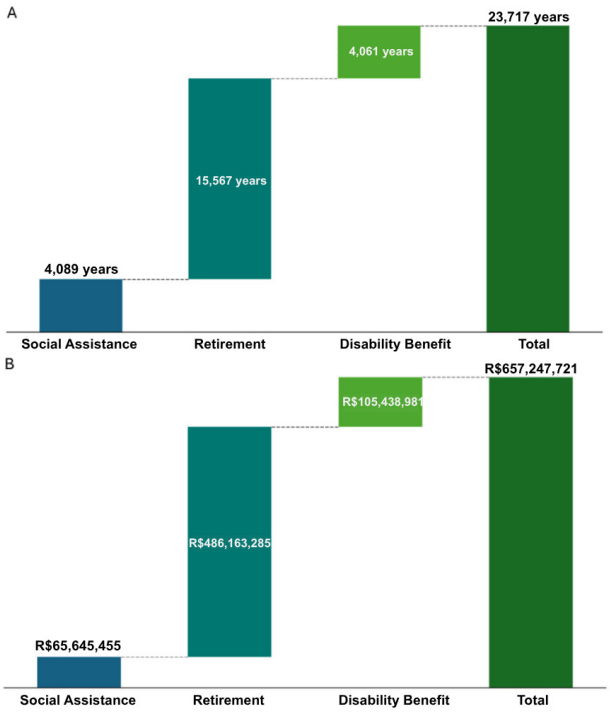


Table 2. Individual Economic Burden by Type of Benefit

Outcome	Social Assistance	Retirement	Disability Benefit	Total
Total n (%)	1,167.00 (7.29)	3,175.00 (19.82)	11,676.00 (72.89)	16,018.00
Duration (months), median (IQR)	26.57 (12.69-72.99)	59.35 (32.76-81.83)	4.00 (4.00-4.00)	4.00 (4.00-11.72)
Number of minimum wages, median (IQR)	1.00 (1.00-1.00)	1.32 (1.00-2.19)	1.22 (1.00-1.88)	1.17 (1.00-1.86)
Total expenditure (R$), median (IQR)	35,886.25 (17,259.64-97.409.61)	116,395.36 (65,029.16-195.637.98)	6,455.78 (5,321,60-10.606.80)	8,764.22 (5,359,56-24,641.46)

IQR - Interquartile Range.

Figure 3. Cumulative Economic Burden by Type of Benefit



A. Cumulative duration of benefits (in years) by type of benefit.

B. Cumulative expenditure by type of benefit (in Brazilian Reais, adjusted for inflation up to December 2023).

Discussion

The present study demonstrated a significant impact of multiple sclerosis (MS) on the Brazilian social security system over the past ten years, resulting in a burden exceeding R$657 million, predominantly attributed to early retirement benefits. The findings reveal not only the economic burden of MS but also the importance of conducting periodic analyses of the indirect costs of diseases to inform occupational and health policy planning in Brazil, especially considering the availability of open data, as used in this research.

Nascimento et al.[18] also used social security indicators to estimate the impact of chronic obstructive pulmonary disease (COPD). Unlike the present study, those authors calculated total expenditure based on benefits maintained by the INSS strictly at the time of analysis (June 2022), whereas our analyses captured benefits granted over a ten-year period. Furthermore, Nascimento et al. considered the retirement age as 65 years or older, regardless of sex, while the present study used sex-specific retirement ages, as defined by the legislation in effect during each year, ensuring a more robust and representative methodology. It is worth noting that, in COPD, retirements were the most frequent benefit (61.53%), followed by social assistance (27.03%) and temporary disability benefits (9.04%), whereas in MS, temporary disability benefits represented 73% of all benefits included. This difference may reflect the ten-year observation period of the present study, which allowed a better capture of short-term benefits.

Additionally, temporary disability benefits, although of shorter duration, generated higher cumulative costs than social assistance benefits, with a similar total duration of benefit periods. This likely reflects the episodic nature of MS, characterized by relapsing and remitting periods, progressive symptom aggravation, and the occurrence of comorbidities. It may also be influenced by the different forms of MS (relapsing-remitting, primary progressive, and secondary progressive), which have distinct prognoses and costs,[19] highlighting the importance of early detection and treatment strategies, as demonstrated by international evidence.[20]

The cumulative time and cost of individual benefits over the analysis period represent a significant financial loss for the country—with general medians of four months of work leave and R$8,764.22 in expenditure per benefit, comparable to the annual productivity loss estimate of R$6,517.00 reported by Kobelt et al.[10] based on lost workdays relative to GDP per capita. However, this burden does not include other indirect impacts such as team productivity loss, employer costs, and effects on the income, organization, and quality of life of individuals with MS and their families. The mean age below 40 years at the time of benefit concession suggests that the 20% of early retirement cases may pose a challenge to the replacement of these individuals (human resources) in the labor market.

The geographical distribution of benefits aligns with the GBD study's prevalence data for different Brazilian regions (lowest in the North, followed by

the Northeast, Central-West, Southeast, and South),[5] except for the Southeast, which had nearly three times as many benefits as the South. This pattern also corresponds to the regions with higher proportions of employed individuals contributing to social security.[21] Among federative units, the Federal District, which had the highest average annual benefit rate, ranks third in prevalence, behind Santa Catarina and Rio Grande do Sul. Inequality in access to health services in Brazil likely affects the prevalence and distribution of MS-related benefits. Despite improvements over the past 30 years with the expansion of the Unified Health System (SUS), considerable territorial disparities in infrastructure, human resources, and other factors remain,[22] as evidenced by the unequal distribution of MRI scanners across regions.[4] Further studies are needed to better understand the relationship between benefit distribution and prevalence, especially through the characterization of populations receiving early social security benefits by region and MS subtype, as well as exposure to risk factors.

Similarly, although the number of benefits observed in this study reflects the higher prevalence of MS among women,[1,2] the available data do not allow precise determination of the exact proportion of female and male beneficiaries, since an individual may have received more than one benefit.

Globally, the cost of MS is high, encompassing both direct costs (medical expenses associated with hospitalizations, consultations, and medications) and indirect costs, which include short- and long-term disability, absenteeism, employment benefits, and early retirements.[19] A study conducted in Germany[23] estimated an average cost of €41,316 per patient per year, with approximately 32% of this cost attributed to early retirement. However, as noted by Adelman et al.,[19] methodological differences among studies make direct comparisons between cost estimates challenging.

Considering these aspects, the present study has some limitations, including the inability to categorize benefits by disease severity, as the databases do not provide detailed clinical information about beneficiaries. Consequently, it was not possible to outline a precise clinical profile of MS patients receiving benefits, which could have informed targeted actions to mitigate the economic and personal impact of MS. Moreover, it is possible that the same individual received multiple temporary disability benefits over time or a sequence of temporary and retirement benefits. However, the available data do not allow for the assessment of such temporal relationships.

The analyses were based on projections of benefit duration using conservative assumptions, which tend to underestimate the total burden, including adjustments for MS-specific mortality.[16] On the other hand, this study was pioneering in using open-access data on MS, analyzed with a robust methodology, generating relevant evidence for both the Brazilian social security system and, indirectly, for the health system, by emphasizing the importance of prevention and early management of this chronic disease that affects individuals during their productive years.

Conclusion

MS imposes a significant economic burden on the Brazilian social security system, as evidenced by the large number of short-term disability benefits, which cumulatively lead to substantial financial impact and productivity loss, as well as by early retirements, granted approximately 19 years before the current minimum retirement age.

Authors' Contributions

MAZM: Study design, methodology validation, data collection and analysis, results interpretation, manuscript drafting and review, approval of the final version.
KCB: Study design, methodology validation, supervision of data analysis, results interpretation, manuscript drafting and review, approval of the final version.
RAR: Study design, methodology validation, supervision of data analysis, results interpretation, manuscript review, approval of the final version.

Conflicts of Interest

The authors declare no conflicts of interest.

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Data Availability Statement

Data are available upon request from reviewers.

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