



ORIGINAL ARTICLE

The cost of dementia in Brazil

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Objective: Given the increasing number of people with dementia in Brazil, health and social systems must urgently plan strategies to meet the needs of this population and their families. Therefore, research on dementia costs is essential. This study estimated direct and indirect dementia-related costs in Brazil.

Methods: We used a cost-of-illness methodology to estimate dementia-related costs, in addition to household interview data from the National Report on Dementia in Brazil (ReNaDe) and public national databases to collect data on health service use and costs. Both a social and a health system perspective were used.

Results: The monthly cost of dementia per patient increases with advancing stages of the syndrome: USD 843.04 in the initial stage, USD 1,317.81 in the intermediate stage, and USD 1,576.15 in the advanced stage. Indirect costs represent $\geq 73\%$ of total expenses. The country's total expenses are the highest during the intermediate stage of dementia.

Conclusion: Family caregivers shoulder at least 73% of the health-related costs of dementia in Brazil, highlighting the need for better support strategies for people with dementia and their families.

Keywords: Cost-of-illness; costs and cost analysis; dementia; Alzheimer disease; public health

Introduction

Dementia is a progressive syndrome that currently has no cure, demanding continuous supervised care, especially in advanced stages. This syndrome is one of the most disabling clinical conditions among older adults, profoundly impacting patients, their families, and society at large.¹

The escalating costs of dementia are a challenge to global health and social care systems.² Global data indicate a steady increase in dementia-related expenses, from USD 604 billion in 2010 to USD 1.3 trillion in 2019.² Remarkably, over half of this expenditure arises from informal care,² i.e., the support given to people with dementia by individuals without a formal employment contract and who receive no financial compensation, in other words, care provided by family, friends, or neighbors, who are predominantly women.

Over 60% of individuals with dementia reside in low- and middle-income countries (LMIC). These countries expend more on informal care costs than high-IC (HIC), accounting for 65% of total dementia-related costs.³ This burden is exacerbated by the fact over 70% of the hours dedicated to informal caregiving globally occur in LMIC.³

In Latin America, comprehensive data on dementia-related costs are sparse. However, available estimates indicate significant variation, with annual costs per person

ranging from USD 3,375.00 to USD 13,488.00 in South America.⁴ For instance, an Argentinian study reported that dementia costs nearly triple between the initial and advanced stages, with further increases once a person is institutionalized.⁵ Disease progression not only increases costs, but leads to an increased care burden for informal caregivers as neuropsychiatric symptoms increase, and the patient becomes more dependent in activities of daily living.⁶

In Brazil, dementia is projected to intensify significantly. Estimates indicate that 1.8 million Brazilians were living with dementia in 2019, and this number is expected to more than triple by 2050.⁷ This anticipated surge underscores the urgency for national health and social systems to adequately prepare for the needs of people with dementia and their families.

Caregivers of individuals with dementia often find themselves compelled to interrupt their careers and educational pursuits, compromising their financial autonomy to assume the role of full-time or near-full-time caregivers. This situation often strains family finances, since the caregiver earnings are forfeit or reduced.^{3,8} Notably, a study conducted at an outpatient clinic in São Paulo reported that nearly two-thirds of dementia-related costs derive from informal caregiving, with the majority of this cost related to time spent in patient care.⁹ However,

this was a small study in conducted in the country's wealthiest state.

Given the dearth of research on the direct and indirect costs of dementia in Brazil and considering the country's geographic diversity, it is essential to determine the current allocation of health resources to be able to (re) direct them to better meet the needs of people with dementia and their families.

Methods

This study is part of the National Report on Dementia (Relatório Nacional sobre a Demência no Brasil - ReNaDe), a partnership between the Brazilian Ministry of Health and the Hospital Alemão Oswaldo Cruz via the Brazilian Public Health System's Institutional Development Program (Programa de Apoio ao Desenvolvimento Institucional do Sistema Único de Saúde [PROADI-SUS]). The project was funded by the Brazilian Ministry of Health.

We used the cost-of-illness methodology to estimate dementia-related costs in Brazil. This approach allowed us to estimate social expenditure on the disease, identify different cost components, and project potential savings if the disease were eradicated. Cost-of-illness estimates can also help set priorities and pinpoint inefficiencies in care provision for affected individuals.^{10,11}

Data collection

Approaches

Household interview data from the ReNaDe project (detailed in the Data Source section) informed this study's bottom-up approach. Conversely, for the top-down approach, we used public databases, such as the Unified Health System Database (DATASUS), the Procedures, Medications, Orthoses/Protheses, and Special Materials Pricing Management System (Sistema de Gerenciamento da Tabela de Procedimentos, Medicamentos e OPM do SUS - SIGTAP), and the Health System Price Databank (Sistema Banco de Preços em Saúde) for the necessary information to estimate unit costs.

Given that our cost estimates blended both bottom-up and top-down approaches, we did not include confidence intervals or other measures of uncertainty in the results. Descriptions of such statistics would be possible only if our estimates were solely grounded in the bottom-up approach, which presupposes known sample sizes and variances.²

Data sources

The ReNaDe project was conducted in 2023 in 17 large, medium, and small municipalities throughout Brazil, including both urban and rural areas. A questionnaire-based interview was conducted in the homes of people with dementia and their caregivers, all users of the Unified Health System, the national, state-funded, free of charge at the point of use primary health care system, which serves approximately 70% of the population.¹²

The present study included information from 140 patient-caregiver dyads. The majority of the people living with dementia were women (69.3%), with an average age of 81.3 (SD, 7.91) years; 75.7% had < 4 years of education, 22% were in the initial stage of dementia, 38% were in the intermediate stage, and 40% were in the advanced stage. Of the 140 caregivers, 86% were women, with an average age of 57.8 (SD, 12.6) years; 29.3% had between 9 and 11 years of education.

The Resource Utilization in Dementia¹³ instrument included in the questionnaire to collect data on the frequency and type of services/products the patients used, as well as on the care provided by the caregivers.

Official data sources were used to assess both direct and indirect costs. For instance, data from the DATASUS Hospital Information System (Sistema de Informações Hospitalares) were used to estimate the average daily hospitalization costs for various dementia types across national regions.¹⁴ Data on emergency costs were collected from SIGTAP, providing the average cost for any type of emergency,¹⁵ and this system was also used to determine average outpatient consultation costs, as shown in Table 1.

To determine the daily cost of geriatric diapers, an average of four diapers¹⁶ per day was assumed. Costs were then calculated from both the caregiver/patient (social) perspective and the Unified Health System perspective, using the average cost of a single diaper among the four available brands in Brazil's Popular Pharmacy Program (Programa Farmácia Popular do Brasil) for consumers, in contrast with the price the Unified Health System pays.¹⁷

To evaluate medication-related costs, we assumed the maximum daily dosage recommended in the Clinical Protocol and Therapeutic Guidelines for Alzheimer's Disease (Protocolo Clínico e Diretrizes Terapêuticas da Doença de Alzheimer)¹⁸ for specific drugs. Costs from the individual perspective were based on Medication Market Regulation Agency (Câmara de Regulação do Mercado de Medicamentos) listings, which include the maximum consumer prices plus an 18% tax on goods and services.¹⁹ Unified Health System costs were determined using the Health System Price Databank (Sistema Banco de Preços em Saúde), considering the lowest price per medication according to the Department of Health Logistics (Departamento de Logística em Saúde).²⁰

Indirect care costs were determined using the replacement costs approach.² This method assumes an hourly rate for informal caregivers (i.e., a family member providing unpaid care) equal to that of formal caregivers. The hourly rate of formal caregiver was based on the average wages of caregivers for older adults in Brazil, as documented in the New General Register of Employment and Unemployment (Cadastro-Geral de Empregados e Desempregados).²¹ An alternative analysis was conducted using the average Brazilian salary based on the 2022 National Household Sample Survey (Pesquisa Nacional por Amostra de Domicílios Contínua)²² to further clarify costs.

All data collected from official data sources were for the years 2022 or 2023, based on availability.

Table 1 Types of direct and indirect medical costs, data sources, reference year, and average cost in dollars

Direct costs	Data source	Reference year	Average cost (USD)
Services used for the care of people living with dementia			
Hospitalizations	SIH (DATASUS)	2022	31.78
Emergencies	SIGTAP	2023	5.05
Outpatient consultations with healthcare professionals			
General practitioner	SIGTAP	2023	4.05
Neurologist	SIGTAP	2023	4.05
Geriatrician	SIGTAP	2023	4.05
Psychiatrist	SIGTAP	2023	4.05
Physiotherapist	SIGTAP	2023	2.55
Occupational therapist	SIGTAP	2023	2.55
Social worker	SIGTAP	2023	2.55
Psychologist	SIGTAP	2023	2.55
Nurse	SIGTAP	2023	2.55
Products used to care for patients with dementia			
Geriatric diapers	Community: average of 4 pharmacies and 4 brands SUS: PFPB	2023	Community: 1.40 SUS: 0.26
Medications (donepezil, galantamine, rivastigmine, and memantine)	Community: CMED SUS: BPS	CMED (2023) BPS (Oct 2022 to Oct 2023)	PCDT Alzheimer
Professional support			
Caregiver or assistant	Novo CAGED	2022	3.31
Indirect costs			
Caregiver hours spent helping patients with activities of daily living (per hour)			
Basic activities of daily living	Novo CAGED	2022	3.31
Instrumental activities of daily living	Novo CAGED	2022	3.31
Exclusive supervision	Novo CAGED	2022	3.31
Work hours the caregiver forfeited to provide informal care for a person with dementia (per hour)	Novo CAGED	2022	3.31

BPS = Health System Price Databank (Sistema Banco de Preços em Saúde); CMED = Medication Market Regulation Agency (Câmara de Regulação do Mercado de Medicamentos); DATASUS = Unified Health System Database; Novo CAGED = New General Register of Employment and Unemployment (Cadastro-Geral de Empregados e Desempregados); PCDT Alzheimer = Clinical Protocol and Therapeutic Guidelines for Alzheimer's Disease (Protocolo Clínico e Diretrizes Terapêuticas da Doença de Alzheimer); PFPB = Brazilian Popular Pharmacy Program (Programa Farmácia Popular do Brasil); SIGTAP = SUS Procedures, Medications, Orthoses/Protheses, and Special Materials Pricing Management System (Sistema de Gerenciamento da Tabela de Procedimentos, Medicamentos e OPM do SUS); SIH = Hospital Information System (Sistema de Informações Hospitalares); SUS = Unified Health System.

Analysis perspectives

Our analyses considered two cost estimation perspectives:

1. The social perspective (applied to all estimates, such as the monthly cost of dementia per person, the proportion of indirect costs, and the annual cost of dementia).
2. The Unified Health System perspective (considering the system as a service-purchasing entity, which was used to estimate the average annual and monthly costs of dementia, etc.).

Incorporating these two perspectives is pivotal since costs can differ for each item depending on the perspective. Thus, we present estimates from both social and health system perspectives to illustrate potential cost variations.

All analyses were conducted separately for each stage of dementia (initial, intermediate, and advanced).

Cost types

Total cost encompasses both direct medical costs and indirect costs (Table 1). Direct medical costs refer to

formal health service use, including hospitalizations, outpatient visits, and medication purchases. Indirect costs refer to informal care provided by family, friends, or neighbors, for instance, the monetary value of hours spent providing care for people with dementia, as well as the caregiver's lost productivity.

We did not factor in direct social (non-medical) costs (e.g., long-term care facilities, day centers, home care, meal delivery services, respite care for caregivers, etc.) in our analyses for two primary reasons: first, due to the unavailability of some of these services in Brazil, and second, due the limited data on the cost and usage of these services (e.g., long-term care facilities and day centers) by people with dementia. The intangible costs of dementia, such as suffering, were not considered in this study.

Additional considerations

The national cost estimates were initially based on dementia prevalence data from the 2023 Brazilian Delphi Consensus,²³ which engaged 15 dementia researchers from the country's five regions. This consensus estimated that 2.5 million Brazilians were living with dementia in 2019. For comparative purposes, we calculated some estimates using data from the Global Burden of Disease Study,⁷ which calculated 1.8 million dementia cases in Brazil for the same year.

Population figures for this study are based on 2019 statistics, with 2022 data occasionally referenced for comparison.²⁴

Costs were originally calculated in Brazilian reais (BRL). All monetary values are presented in USD, and adjustments for economic indicators were applied where necessary. Exchange rates are based on December 2023 purchasing power parity data from the Institute of Applied Economic Research.²⁵

This study's estimates are based solely on diagnosed dementia cases. However, the period surrounding a dementia diagnosis incurs significant costs, with a notable 91% surge during the initial year.²⁶

Ethics statement

The ReNaDe project was approved by the research ethics committee of Hospital Alemão Oswaldo Cruz (decision 58125222.6.0000.0070), and all participants provided written informed consent.

Results

The results are divided into the social and health system cost perspectives.

Social perspective

The monthly cost of dementia per individual increases with the syndrome's progression: from USD 843.04 in the initial stage, to USD 1,317.81 in the intermediate stage, to USD 1,576.15 in the advanced stage (Table 2).

Indirect costs, primarily associated with informal care provided by family or friends, constitute at least 73% of total expenses, irrespective of dementia stage (Table 2). Thus, people with dementia and their families shoulder over two-thirds of the financial burden. Broken down by stage, indirect costs account for 78.5% and 81.8% in the initial and moderate stages, respectively, dropping slightly to 72.9% in the advanced stage.

The total cost of dementia in Brazil in 2019 was USD 9.7 billion in the initial stage, USD 14.4 billion in the intermediate stage, and USD 11.2 billion in the advanced stage: cumulatively, USD 35.3 billion, of which 78% were indirect costs. Direct dementia-related costs in 2019 represented 0.15% of Brazil's gross domestic product (GDP). Considering 2022 population data, the annual cost of dementia was projected at USD 39.1 billion, reflecting population aging and the consequent rise in dementia cases.

Nevertheless, these cost estimates depend on dementia prevalence data. Based on Global Burden of Disease estimates,⁷ Brazil's dementia costs in 2019 totaled USD 26.5 billion (USD 7.3 billion, USD 10.8 billion, and USD 8.4 billion in the initial, intermediate, and advanced stages, respectively).

Table 2 Breakdown of average monthly direct and indirect costs per capita, with percentages relative to total costs per dementia stage

Dementia stages	Initial		Intermediate		Advanced	
	Average monthly per capita cost (USD)	Proportion of total cost (%)	Average monthly per capita cost (USD)	Proportion of total cost (%)	Average monthly per capita cost (USD)	Proportion of total cost (%)
Total direct medical costs	180.60	21.43	214.37	18.20	426.68	27.07
Total indirect costs	662.43	78.57	1,077.94	81.80	1,149.47	72.93
Total costs	843.04	100.00	1,317.81	100.00	1,576.15	100.00
Proportion of the average annual cost by stage of dementia progression (%) [†]	27.5		40.8		31.1	

[†] Source: Delphi Consensus.²³

Table 3 Average monthly Unified Health System costs (direct, indirect, and total costs per person), categorized by dementia stage

	Dementia stages		
	Initial	Intermediate	Advanced
Direct costs	62.9	90.2	223.8
Indirect costs	662.4	1,077.9	1,149.5
Total costs	725.3	1,168.1	1,373.3

Data presented as U.S. dollars.

Although the average individual cost is higher in the advanced stage, considering the proportion of the population at each stage of the syndrome, total national expenses are highest for those in the intermediate stage. Effectively, 27.5% of total costs are for the initial stage, 40.8% for the intermediate stage, and 31.1% for the advanced stage (Table 2).

We used the average Brazilian hourly wage from 2022 to refine indirect cost estimates. The monthly dementia costs per person were USD 1,468.6 in the initial stage (direct costs: USD 180.6; indirect costs: USD 1,288.0), USD 2,335.2 in the intermediate stage (direct costs: USD 239.9; indirect costs: USD 2,095.4), and USD 2,661.0 at the advanced stage (direct costs: USD 426.7; indirect costs: USD 2,234.3).

We also analyzed the hours spent assisting with basic and instrumental activities of daily living as an indirect cost, omitting the time allocated for exclusive supervision. As a result, the average monthly cost per person was USD 690.1 in the initial stage (direct costs: USD 180.6; indirect costs: USD 509.5), USD 1,047.5 in the intermediate stage (direct costs: USD 239.9; indirect costs: USD 807.7), and USD 1,351.6 in the advanced stage (direct costs: USD 426.7; indirect costs: USD 924.9). For this analysis, the value of informal work hours was based on the average salary of a formal caregiver in 2022.

Unified Health System perspective

From the health system perspective, changes in direct costs led to adjustments in overall estimates. Table 3 shows that the average monthly cost of dementia for the Unified Health System also increases with progressive stages: USD 725.3 in the initial stage, USD 1,168.1 in the intermediate stage, and USD 1,373.3 in the advanced stage.

From the health system perspective, the annual cost of dementia in Brazil in 2019 was USD 8.4 billion in the initial stage, USD 12.8 billion in the intermediate stage, and USD 9.7 billion in the advanced stage, totaling USD 30.9 billion. Indirect expenses were a significant portion of the total costs across all dementia stages, accounting for 91%, 92%, and 84% in the initial, intermediate, and advanced stages, respectively.

The proportion of indirect costs from the health system perspective surpassed those of the society perspective. Additionally, in the advanced stage, indirect costs declined in both perspectives, suggesting a rise in direct expenses. This trend could indicate increased reliance

on formal healthcare services during the later stages of dementia, regardless of the analytical standpoint.

Discussion

Our analyses reveal that in Brazil, the average expenses for each patient escalate as dementia progresses for both the health system and society at large. Such findings align with prior studies documenting global dementia-related expenditure estimates.^{3,27,28}

A significant portion dementia-related costs (40.8%) occur in the intermediate stage, which might be attributed to the larger proportion of individuals diagnosed in this particular stage, a trend acknowledged in the literature.^{9,29} Another plausible explanation for the elevated costs during this stage could be the omission of social expenses (like those linked to long-term care facilities) from our calculations. If included, such costs could increase expenses in the advanced stage.

Our results indicate that, considering only healthcare expenses, a minimum of 73% of the total cost across all dementia stages is indirect. This includes informal, uncompensated care provided predominantly by family, friends, or neighbors. The large proportion of indirect costs mirrors estimates from several countries²⁸ and accentuates the pivotal role that family caregivers assume in dementia care. The essential role of family caregivers was highlighted in a Spanish study,²⁸ which reported that limited or infrequent use of formal healthcare resources leads family members to be the primary caregivers for people with dementia.

The significant emphasis on informal care, accounting for over two-thirds of all provided care, and the predominant role of women in caregiving for dementia patients, were also highlighted in a study of 156 caregivers for dementia patients at a university outpatient clinic in São Paulo.⁹ While Ferretti et al.⁹ gathered information solely from a bottom-up approach (interviewing caregivers of dementia patients and collecting individual data) in a specific setting (an academic outpatient clinic in the country's wealthiest state), the present study estimated costs based on a mixed approach (bottom-up and top-down), collecting data through interviews with dementia patients and their caregivers in each region of the country, as well as from national data sources. Although these studies used different methodologies, both show the importance of informal care in dementia. However, the present study found that informal care costs are high regardless of the cost perspective (society or health system). These findings resonate with findings from

international research,^{9,28} such as Ferretti et al.,⁹ who described the multifaceted toll caregiving takes on the well-being (mental, physical, emotional, and financial) of caregivers.¹¹ Such findings highlight the urgent need to address the care requirements of these caregivers, particularly women.

A 2023 global assessment of dementia-associated expenses categorized nations according to economic status,² determining the relationship between the direct costs of dementia and national GDP for 2019. Despite being considered an upper-MIC,³⁰ our estimate that Brazil's direct dementia costs in 2019 were about 0.15% of its GDP closely aligns with the figures for LIC and LMIC (0.17% and 0.11%, respectively) found in the global assessment.² Meanwhile, dementia direct costs were 0.37% and 1% of the GDP of MIC and HIC, respectively.² However, the same study found that the proportion of informal care costs is higher in LMIC than HIC (64.7 vs. 44.3%, respectively). Because social costs could not be considered in our estimates, the proportion of informal care-related costs in Brazil ($\geq 73\%$) is higher than that of HIC and LMIC in the aforementioned study. Brazil's indirect cost estimates are closer to those of LMIC (75.9%).²

A study assessing the economic impact of cancer in Brazil between 2010 and 2015 found that direct costs represented an average of 1.7% of the Brazilian GDP,³¹ indicating that the direct costs of dementia are approximately one-tenth of those for cancer during this period. Brazil's indirect dementia-related costs in 2019, i.e., 78% of the estimated USD 35.3 billion, is roughly equivalent to 3.6 billion in compensation for caregivers (considering any diagnosis, not just dementia).

A Chilean study²⁸ found that direct health costs related to dementia increase in higher socioeconomic groups (indicative of purchasing power disparities). Conversely, indirect costs weigh more heavily on groups with lower socioeconomic status. Given Brazil's pronounced social inequality, further research should investigate dementia-related costs according to socioeconomic standing.

Several limitations are inherent to our cost estimates, which could result in underestimation. A notable constraint was the limited availability of specific social services data related to dementia, which precluded calculation of direct social costs. Additionally, the pivotal phase of dementia diagnosis, often one of the most expensive stages in the process, was not factored into our estimates.²⁶ It is important to note that our estimates assume that all affected individuals have been diagnosed and are receiving treatment. However, substantial under-diagnosis can be expected in real-world scenarios, prompting greater treatment seeking, such as hospitalizations or emergency care, than would occur with timely diagnosis and appropriate support.

The data we used for our estimates drew from existing epidemiological studies, factoring in the total population with dementia and its distribution across initial, intermediate, and advanced stages. The costs are derived from national databases, which may occasionally provide outdated or inconsistent market values. It is also

important to note that our cost assessments might not encompass all potential expenses associated with dementia, such as home renovations or adaptations.

It has been suggested² that dementia cost estimate studies should ideally identify all individuals diagnosed with the syndrome and determine their stage of progression (initial, intermediate, or advanced). Comprehensive data on service use and associated costs should be segmented according to dementia stage, including records of available support types, caregiver sociodemographic characteristics, caregiver types, quantification of hours dedicated to dementia care, and comprehensive details on the organization, financing, and reimbursement for care. In this ideal scenario, there should also be consensus on how to attribute monetary value to the care provided by families and other caregivers to people with dementia.² However, such an ideal scenario remains a distant goal both globally and in Brazil. A consistent challenge across countries is inconsistent documentation of dementia-related data, which introduces significant uncertainties in cost analyses.² This situation, in turn, hampers the monitoring and reliability of care-related data, including health and social assistance services for dementia care.

Although we are aware of this study's limitations and that there may be no ideal scenario for estimating the costs of dementia, this report offers important insights into dementia-related costs in Brazil, where such data remain sparse. Our methodology facilitates a nuanced understanding of costs linked to formal and informal dementia care, shedding light on the often-overlooked area of informal caregiving. We included social and health system cost perspectives, which could help stakeholders with decision-making. To our knowledge, no prior studies have considered socioeconomic disparities in each region of Brazil when assessing the cost of dementia. Insights gleaned from home interviews during the ReNaDe project have enriched our understanding of different living conditions and service usage patterns, which contributed to the accuracy of our cost estimates.

We hope that this study's findings will contribute to a better understanding of the distribution of dementia-related costs in Brazil and inform policymakers about the considerable proportion of care that informal caregivers provide and the lack of support they receive. Allowing caregiving time to count towards retirement benefits and equipping healthcare systems to anticipate and manage the projected surge in demand for dementia-related services would be significant first steps toward prioritizing the well-being of people with dementia and their caregivers.

Disclosure

The authors report no conflicts of interest.

Author contributions

FAFM: Conceptualization, data curation, formal analysis, investigation, methodology, writing – original draft, writing – review and editing.

AAR: Conceptualization, data curation, investigation, methodology, writing – original draft, writing – review and editing.

LB: Conceptualization, data curation, investigation, methodology, writing – original draft, writing – review and editing.

TS: Data curation, methodology, writing – review and editing.

CPF: Conceptualization, data curation, formal analysis, investigation, methodology, writing – original draft, writing – review and editing.

HAOJ: Conceptualization, data curation, formal analysis, investigation, methodology, writing – original draft, writing – review and editing.

All authors have read and approved of the final version to be published.

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