Research Square

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National portrait of amyotrophic lateral sclerosis care in Brazil's Unified Health System (2023–2025): patient-level treatment, persistence, and geographic access from linked administrative microdata

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Abstract

Background

Amyotrophic lateral sclerosis (ALS) is a progressive motor neuron disease for which riluzole remains the main disease-modifying therapy available in many health systems. Nationwide, patient-level descriptions of ALS care pathways in low- and middle-income countries with universal health coverage are scarce. We aimed to characterize ALS treatment, treatment persistence, and geographic access within the Brazilian Unified Health System (SUS) using nationwide administrative microdata.

Methods

We conducted a retrospective nationwide study using deidentified administrative microdata from SUS between January 2023 and December 2025. We identified patients at the individual level using an encrypted national health identifier based on the ICD-10 code G12.2 and/or riluzole dispensing, an ALS-specific treatment marker in Brazil. Ambulatory services and care centers were analyzed at the aggregate level. Treatment persistence was estimated using Kaplan-Meier methods. Geographic access was assessed by comparing the distribution of treated patients with expected ALS prevalence estimates across Brazilian states.

Results

We identified 10,598 patients receiving ALS-related treatment and 890 probably diagnosed but untreated patients, corresponding to an estimated treatment gap of approximately 7.7%. Median age at first record was 62 years, and the male-to-female ratio was 1.22:1. Among patients with available race and ethnicity information, 54.4% were classified as White, 38.3% as mixed, and 3.9% as Black. Riluzole dispensing was monthly in 94.6% of observed intervals; median treatment persistence was 19 months (95% CI 18–20), with 61.4% of patients remaining on treatment at 12 months and only 35.3% achieving a medication coverage proportion of at least 0.80. Rehabilitation services represented most ambulatory care contacts, whereas ALS-specific diagnostic coding was rarely captured in SUS administrative data. Medication dispensing and multidisciplinary clinical care were structurally separated across care sites. Treatment coverage demonstrated substantial regional variation, with markedly lower capture in northern states, including Acre (38%), Roraima (39%), and Amazonas (47%).

Conclusions

Within the SUS, ALS treatment availability approached the expected population burden overall, but important inequities remained in treatment continuity, geographic access, and diagnostic recognition.

These findings highlight the need for improved diagnostic pathways, active identification of patients with ALS, and integrated regional networks for multidisciplinary care.

1. Introduction

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disorder characterized by relentless motor neuron degeneration and a median survival of approximately 2–4 years from symptom onset[1, 2]. The pooled prevalence is estimated at 4.42 per 100,000 people worldwild, the incidence is estimated at 1.59 per 100,000 person-years[3, 4] and the absolute burden is projected to increase with increasing population age[5].

Riluzole was the first disease-modifying therapy approved for ALS and remains the cornerstone of pharmacological treatment in many healthcare systems. Although its survival benefit is modest, it has been consistently demonstrated across randomized trials and meta-analyses[6–8], making sustained treatment an important component of disease management. In addition, multidisciplinary care delivered through specialized ALS clinics independently improves survival and quality of life[9–11]. Together, these findings highlight that effective ALS care depends not only on treatment availability but also on timely diagnosis, continuity of therapy, and access to coordinated multidisciplinary services.

Brazil provides universal healthcare through the Unified Health System (*Sistema Único de Saúde* (SUS)), a tax-funded public system serving more than 200 million people. Riluzole is provided free of charge through the Specialized Component of Pharmaceutical Assistance (*Componente Especializado da Assistência Farmacêutica* (CEAF)). Under the National Clinical Protocol and Therapeutic Guidelines (PCDT)[12], neurologists establish the diagnosis and submit a standardized administrative request for treatment, after which medication is dispensed through state-managed CEAF pharmacies with periodic renewal of authorization. Although this pathway is nationally defined, its implementation depends on state and local health services, potentially creating regional variation in access to diagnosis and treatment. Consistent with these challenges, diagnostic delays in Brazil remain prolonged, with reported intervals of approximately 23 months from symptom onset to diagnosis[13], mirroring difficulties described internationally[14].

The Brazilian public health system routinely generates nationwide administrative health data through the Department of Informatics (DATASUS), including information from the Hospital Information System (SIH) and the Outpatient Information System (SIA), patient-level Authorizations for High-Complexity Procedures (APAC) records and outpatient production (PA) records. These databases provide a unique opportunity to evaluate healthcare delivery on a national scale. However, existing Brazilian evidence remains fragmented, consisting primarily of a voluntary national survey,[15] regional and single-center clinical cohorts[13, 16–18], an ongoing national ALS registry[19], and a single-year aggregated administrative analysis presented in abstract form[20]. The Brazilian National ALS Registry and Observatory (RevELA) represents an important complementary initiative for prospective clinical surveillance but has not yet generated nationwide patient-level analyses[19].

Consequently, important aspects of ALS care delivery, particularly treatment continuity, geographic access, and the organization of care within the public healthcare system remain poorly characterized at the national level. We therefore asked, at the national and individual levels, who is treated, how long they persist in therapy, and how access is distributed geographically, using linked SIH/SIA microdata for 2023–2025.

2. Materials and methods

2.1 Study design, setting, and period

We conducted a nationwide, retrospective, population-based study using deidentified administrative microdata from DATASUS. The study covered the period from January 2023 to December 2025, the period with consistent nationwide data availability (December 2025 partial). Record-level files were reconstructed into a columnar analytical database while preserving data provenance. Sparse records before 2023 (< 0.2% of all observations) were retained but had no material impact on patient-level analyses.

2.2 Data sources

The data sources are summarized in Table 1. Three nationwide administrative databases were analyzed. Patient-level outpatient data, which include riluzole dispensing records and procedure reports linked through an encrypted National Health Card (*Cartão Nacional de Saúde* (CNS)) were obtained from the APAC and SIA/SUS systems. Hospitalizations were obtained from the SIH, where admissions were analyzed as independent events, keyed by admission, and analyzed at the event level only. Ambulatory production data (PA, SIA/SUS) contain no patient identifier and were therefore used exclusively to characterize healthcare service volume at the municipality and healthcare-establishment levels. Accordingly, all PA-derived measures represent service volume rather than patient counts.

Table 1
Data sources, identifiers, and analytical role (2023–2025).

System	Content	Patient key	Role
APAC-Med	Riluzole dispensing	Encrypted CNS	Treatment (patient-level)
APAC (proc.)	Procedures/reports w/ ICD	Encrypted CNS	Diagnosis (patient-level)
SIH (RD)	Inpatient admissions	Admission (AIH)	Hospitalization events
SIA (PA)	Ambulatory production	None	Service & center map (aggregate)

2.3 Case definition

Riluzole (procedure code 0604540019) is dispensed through SUS in Brazil exclusively for ALS under the CEAF and was therefore used as a disease-specific treatment marker.

Using patient-level APAC records, patients were classified into three mutually exclusive groups: confirmed treated (ICD-10 G12.2 with riluzole dispensing; primary study population), diagnosed but untreated (ICD-10 G12.2 without riluzole dispensing, further classified according to diagnostic-code persistence as a single month or ≥ 3 consecutive months), and coding leakage (riluzole dispensing without ICD-10 G12.2).

A single riluzole dispensing generates records in two SUS subsystems: a patient-level authorization (APAC-Medicaments) and an aggregate outpatient-production (PA) record. Because these represent the same dispensing event rather than independent treatments, treatment ascertainment relied exclusively on APAC-Medicaments, which captured approximately 99.9% of all patient-level riluzole dispensations nationwide, thereby avoiding duplicate counting.

2.4 Variables

The following variables were extracted: age, sex, race/color (coded according to the Ministry of Health Ordinance SAS No. 719/2007[21], municipality of residence, healthcare establishment (National Registry of Health Establishments (CNES)), and competence month. Healthcare establishments were identified using the official CNES registry. Geographic displacement was assessed by comparing the municipality of residence with the municipality of care in PA records and by the interstate-care indicator available in APAC.

2.5 Statistical analysis

Continuous variables are presented as medians with interquartile ranges (IQRs), and categorical variables are presented as proportions with 95% Wilson confidence intervals. As a data-validation step preceding persistence analysis, the distribution of intervals between consecutive dispenses was examined to confirm a monthly dispensing pattern and thereby justify the discontinuation threshold.

Treatment persistence was estimated using Kaplan-Meier analysis from the first observed riluzole dispensing. Treatment discontinuation was defined as a dispensing gap of at least 90 days without subsequent reinitiation, with administrative right-censoring in December 2025. The median persistence with 95% confidence intervals and the proportions remaining on treatment at 6, 12, 18, and 24 months were reported. A sensitivity analysis using a 60-day discontinuation threshold was performed to assess robustness.

Medication coverage was summarized using a proportion-of-covered-month (PDC-like) metric. Continuous variables were compared using the Mann-Whitney U test, and categorical variables were compared using the chi-square test. Expected prevalent ALS cases for each state were estimated by applying the pooled global prevalence (4.42 per 100,000 inhabitants) to the 2022 Brazilian Census population[22] and compared with the observed number of treated patients to estimate relative treatment capture. Exploratory cross-tabulations are presented as hypothesis-generating analyses.

All analyses were performed in Python using the Polars, lifelines, and SciPy libraries.

3. Results

3.1 Case ascertainment and treatment gap

During the study period (2023–2025), 10,598 patients met the definition of confirmed treated ALS (ICD-10 G12.2 with riluzole dispensing), whereas 890 had persistent G12.2 coding (≥ 3 consecutive months) without recorded riluzole dispensing. This yielded an inclusive ALS population of 11,488 patients, corresponding to an estimated treatment gap of 7.7% (Table 2).

Table 2
Case ascertainment (2×2), patient-level (APAC), 2023–2025.

Category	Patients	Interpretation
G12.2 ∩ riluzole	10,598	Confirmed treated (primary)
G12.2, no riluzole, ≥ 3 months	890	Probable diagnosed-untreated
G12.2, no riluzole, single month	1,488	Likely coding noise (excluded)
Riluzole without G12.2	0	Coding leakage (none)
Inclusive ALS population	11,488	Primary + probable untreated
Treatment gap	≈ 7.7%	890 / 11,488

No patient received riluzole without an accompanying G12.2 diagnosis (zero coding leakage), supporting the specificity of riluzole dispensing as an ALS treatment marker. Patients with a single month of G12.2 coding without riluzole (n = 1,488) were classified as probable coding noise and excluded from subsequent analyses (Table 2).

Applying the pooled global ALS incidence (4.42 per 100,000 population) to the 2022 Brazilian Census population (203,080,756 inhabitants)[22], yields approximately 9,000 expected prevalent cases nationwide. The 10,598 treated patients identified during the three-year study period are therefore of a comparable order of magnitude. Because cumulative treated patients over three years and point prevalence are not directly comparable, this analysis was used solely as a contextual comparison and not as an estimate of case ascertainment.

3.2 Demographic profile

Among the 10,598 treated patients, the median age at first recorded dispensing was 62 years. Men accounted for 5,831 patients and women for 4,767, corresponding to a male-to-female ratio of 1.22:1. Race/color was predominantly white (54.4%, 95% CI 53.4–55.3), followed by mixed race (38.3%, 95% CI 37.4–39.2), while black patients represented 3.9% (95% CI 3.5–4.3) (Table 3).

Table 3
Demographic profile of confirmed ALS patients treated with Riluzole (n = 10,598).

Characteristic	Value	Note
Age at first record, median (mean)	62 (61) y	Not symptom onset
Sex, men: women	5,831: 4,767 (1.22:1)	—
White	54.4% (53.4–55.3)	95% CI (Wilson)
Mixed (pardo)	38.3% (37.4–39.2)	—
Black	3.9% (3.5–4.3)	Access/equity signal
Asian / Indigenous / NI	2.5% / 0.03% / 0.9%	—

Women were slightly older than men at the first observed dispensing (median 63 vs. 61 years; Mann-Whitney $p < 0.001$). Because observation was left-truncated, this finding reflects age at first record during the study period rather than age at treatment initiation.

3.3 Treatment persistence

Riluzole dispensing occurred at monthly intervals in 94.6% of observations, whereas 3.5% occurred every two months and 1.0% every three months, supporting the use of a 90-day gap to define treatment discontinuation.

Among patients with at least 12 months of potential follow-up (n = 8,622), median treatment persistence estimated by Kaplan-Meier analysis was 19 months (95% CI 18–20). The percentage of patients remaining on treatment was 75.9% at 6 months, 61.4% at 12 months, 50.8% at 18 months, and 41.2% at 24 months (Fig. 1). A 60-day threshold yielded a near-identical median (18 months), indicating robustness.

The median medication coverage (PDC-like metric) was 0.58, and 35.3% of patients achieved a coverage proportion of at least 0.80.

3.4 Ambulatory care and geographic access

Primary G12.2 coding generated 495,406 outpatient-production records. Rehabilitation and physiotherapy accounted for most outpatient activities (266,424 records across 1,228 municipalities and 1,774 healthcare establishments), followed by outpatient consultations. Procedures specifically coded as ALS diagnostic activity were nearly absent (approximately 2,400 records).

Overall, 22.7% of outpatient services were delivered outside the patient's municipality of residence. This proportion varied according to service type, reaching 66.9% for orthoses and prostheses, 54.9% for laboratory procedures, 45.5% for consultations, 31.5% for imaging, and 16.4% for rehabilitation services (Table 4).

Table 4
Ambulatory service mix and displacement, primary ICD-10 G12.2 (service volume).

Service group	Records	Municipalities	% outside municipalities
Rehabilitation / physiotherapy	266,424	1,228	16.4%
Consultations / assessments	56,886	320	45.5%
OPM (wheelchair/orthoses)	6,902	131	66.9%
Imaging / methods	1,567	105	31.5%

3.5 Center typology and dispensing-care decoupling

Geolocated high-volume centers fell into distinct vocations (Fig. 2). Riluzole dispensing was concentrated in state high-cost pharmacies and state health-secretariat facilities (CEAF logistics), which delivered medication but recorded essentially no clinical service. In contrast, reference rehabilitation centers, including specialized rehabilitation centers (CER), Hospital Júlia Kubitschek, and the SARAH Network, recorded substantial clinical volume but no riluzole dispensing. Only a small number of high-volume establishments corresponded to laboratories or nonneurological facilities, suggesting possible administrative coding imprecision; therefore, these establishments were flagged rather than interpreted as ALS centers.

3.6 Care deserts: north-south access gradient

Relative treatment capture, defined as the ratio between observed treated patients and expected prevalent cases, showed marked geographic variation across Brazil (Fig. 3). The lowest relative capture was observed in the North and parts of the Northeast, including Acre (37.8%), Roraima (39.3%), Amazonas (47.1%), Pará (60.4%), Tocantins (61.2%), Maranhão (65.3%), and Goiás (68.6%). Conversely, several states in the South and Southeast exceeded 100%, including São Paulo (146%), Minas Gerais (160%), and the Federal District (210%). Because patients were assigned according to the state where riluzole was dispensed rather than their state of residence, values above 100% are consistent with interstate referral and treatment flows.

4. Discussion

This nationwide, patient-level study identified important gaps in ALS care delivery within the SUS and demonstrates the potential of routinely collected administrative data to evaluate healthcare delivery at a national scale. By linking publicly available DATASUS records, we reconstructed the ALS care pathway from treatment authorization to medication persistence and healthcare utilization, identifying treatment gaps, marked regional inequalities, and fragmentation of care.

Previous Brazilian studies have relied primarily on regional clinical cohorts, voluntary surveys, and, more recently, a national registry under development[13, 15–20, 23]. Although these studies substantially

advanced the knowledge of the epidemiology and clinical characteristics of ALS, they were not designed to evaluate healthcare organization at the national level.

The demographic characteristics of our cohort were consistent with those of previous Brazilian reports, supporting the validity of our administrative case definition. The modest male predominance, predominance of White patients, and number of treated patients were broadly consistent with regional cohorts and published prevalence estimates[16, 17, 23]. However, administrative databases capture individuals who access healthcare rather than all people living with ALS. Similar limitations have been described for the US National ALS Registry [24], indicating that our estimates are better interpreted as reflecting healthcare coverage than disease prevalence.

One of the most relevant findings was the identification of 890 patients with persistent ALS coding but no recorded riluzole dispensing. Although administrative data cannot distinguish delayed treatment initiation, contraindications, patient preference, administrative barriers, treatment outside the SUS, or geographic limitations, these patients are identifiable within the same administrative pathway used for medication authorization, creating an opportunity for targeted clinical review and quality-improvement initiatives.

Treatment continuity represented a second major challenge. Although medication dispensing followed the expected monthly schedule for most patients, persistence declined progressively, with only 61% remaining on treatment after one year and approximately one-third achieving medication coverage above the commonly accepted 80% threshold. Because riluzole provides a modest but consistent survival benefit that depends on sustained use [6, 8], improving treatment continuity remains an important opportunity to optimize ALS care.

Persistence derived from administrative records should not be interpreted as adherence alone, as death, disease progression, transition to private healthcare, and clinical decisions to discontinue treatment may all contribute to treatment interruption. Brazilian cohorts reporting median survival of approximately 30 months after symptom onset further suggest that mortality contributes to declining persistence[13]. Nevertheless, nationwide monitoring of persistence provides a pragmatic indicator of healthcare delivery that would otherwise require costly prospective follow-up.

Another important finding was the limited visibility of the diagnostic pathway within routine administrative records. ALS diagnosis relies on longitudinal neurological assessment, electrodiagnostic studies, and the exclusion of alternative diagnoses[2, 14], yet these activities were rarely identifiable in our analyses. Consultations and complementary examinations are typically recorded under generic procedure codes, while diagnoses established outside the SUS or before the study period further reduce their visibility. Consequently, the current administrative system provides limited capacity to monitor diagnostic pathways or quantify diagnostic delays. This is particularly relevant because previous Brazilian studies reported delays of 14–23 months between symptom onset and diagnosis[13, 25]. Standardizing diagnostic coding could improve surveillance, facilitate evaluation of referral pathways, and enable monitoring of timely access to treatment.

Geographic inequalities were also pronounced. Relative treatment capture showed a marked north-to-south gradient, while outpatient care frequently required patients to travel outside their municipality of residence, particularly for specialized services. Previous spatial analyses found little evidence of geographic clustering of ALS itself[26], suggesting that these differences primarily reflect healthcare organization rather than disease distribution. These findings highlight regions where access to specialized neurological care may be limited and may help inform regional planning and resource allocation.

The structural separation between medication dispensing and multidisciplinary care has also emerged as an important health-system characteristic. High-cost pharmacies were responsible for dispensing medication, whereas rehabilitation centers and specialized neuromuscular services delivered multidisciplinary care without participating in dispensing. Although this organization reflects CEAF governance, it may increase fragmentation by requiring patients to navigate multiple facilities throughout the disease course. Because multidisciplinary ALS clinics improve both survival and quality of life[9–11], expanding integrated regional reference centers capable of providing diagnosis, pharmacological treatment, rehabilitation, and longitudinal follow-up could simultaneously reduce travel burden, improve treatment continuity, and lessen regional disparities.

Our study has several limitations. The relatively short observation period precluded assessment of temporal trends and differentiation between incident and prevalent treated patients. The estimates of treatment persistence were subject to left truncation and administrative right censoring and should therefore be interpreted conservatively. Because outpatient production records lack patient identifiers, ambulatory analyses reflect service volumes rather than patient counts. Mortality could not be directly ascertained because linkages with death records were unavailable, and treatment discontinuation therefore cannot be distinguished from death, disease progression, or the transition to private healthcare. Finally, comparisons between observed and expected case numbers were intended to evaluate access to treatment rather than estimate true state-specific disease prevalence.

In conclusion, this study demonstrates that publicly available DATASUS records provide a scalable and low-cost approach to monitoring ALS care within a universal health system, without the need for additional reporting systems or prospective data collection. We identified substantial gaps in treatment initiation, treatment persistence, geographic accessibility, and care organization that are largely invisible in conventional surveillance systems. In addition to informing ALS care in Brazil, this approach could support continuous evaluation of healthcare delivery for other diseases managed through administrative databases and guide policies aimed at improving equity and strengthening specialized care.

Declarations

Ethics approval and consent to participate:

This study used publicly available, fully de-identified administrative microdata released by the Brazilian Ministry of Health, with no possibility of individual identification. Under Brazilian National Health Council

Resolutions 466/2012 and 510/2016, research using publicly available, anonymized data does not require research ethics committee approval or informed consent.

Consent for publication:

Not applicable.

Clinical trial number

Not applicable.

Competing interests:

MMN is the founder of DNA MM. BVJP and MET are affiliated with the Paulo Gontijo Institute (IPG). The authors declare that these affiliations did not influence the design, analysis, or interpretation of the study.

Data-access statement

MMN directly accessed and verified the underlying data reported in the manuscript. The data are derived from publicly available, de-identified administrative microdata (DATASUS/SUS); the processed datasets and analysis scripts are available from the corresponding author on reasonable request at miguel.mitne@dnammgroup.com or mmitne@gmail.com

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This work was conducted with internal resources of DNA MM and Instituto Paulo Gontijo. The funders had no role in the study design; in the collection, analysis, or interpretation of data; in the writing of the report; or in the decision to submit the paper for publication.

Author Contribution

MMN conceived and designed the study. MMN curated and processed DATASUS/SUS microdata and conducted statistical analysis. MM and BVJP verified the underlying data. MMN and BVJP drafted the manuscript. All authors contributed to the interpretation of the data, critically revised the manuscript for important intellectual content, had full access to all the data in the study, and approved the final version for submission. MMN had final responsibility for the decision to submit for publication. All authors read and approved the final manuscript.

Data Availability

MMN directly accessed and verified the underlying data reported in the manuscript. The data are derived from publicly available, de-identified administrative microdata (DATASUS/SUS); the processed datasets and analysis scripts are available from the corresponding author on reasonable request at miguel.mitne@dnammgroup.com or mmitne@gmail.com

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Figures

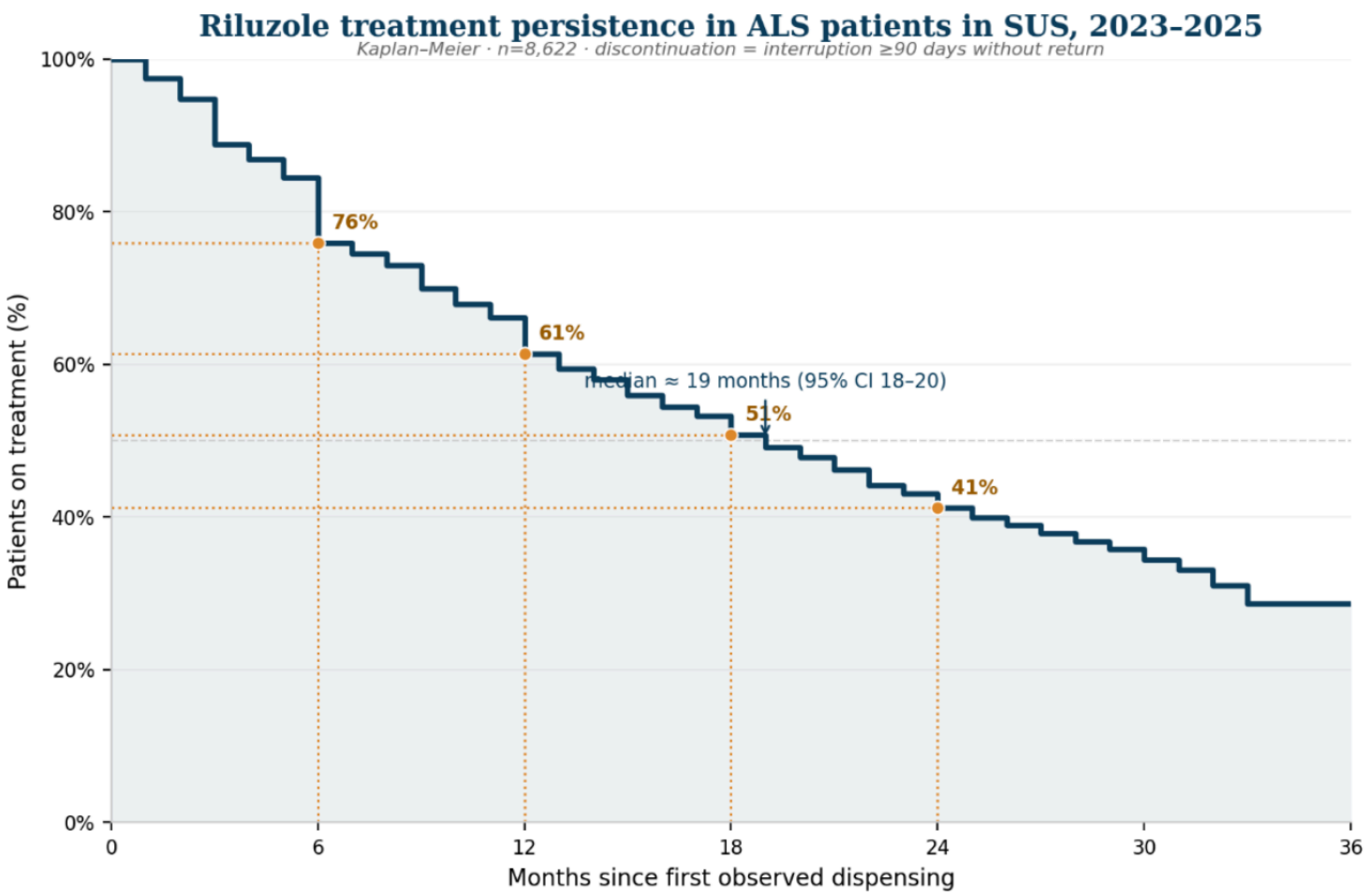


Figure 1

Kaplan-Meier estimate of riluzole treatment persistence. Median treatment persistence was 19 months (95% CI 18–20). The estimated proportions of patients remaining on treatment were 75.9% at 6 months, 61.4% at 12 months, 50.8% at 18 months, and 41.2% at 24 months. Treatment discontinuation was defined as a gap of at least 90 days between dispensing without subsequent reinitiation.

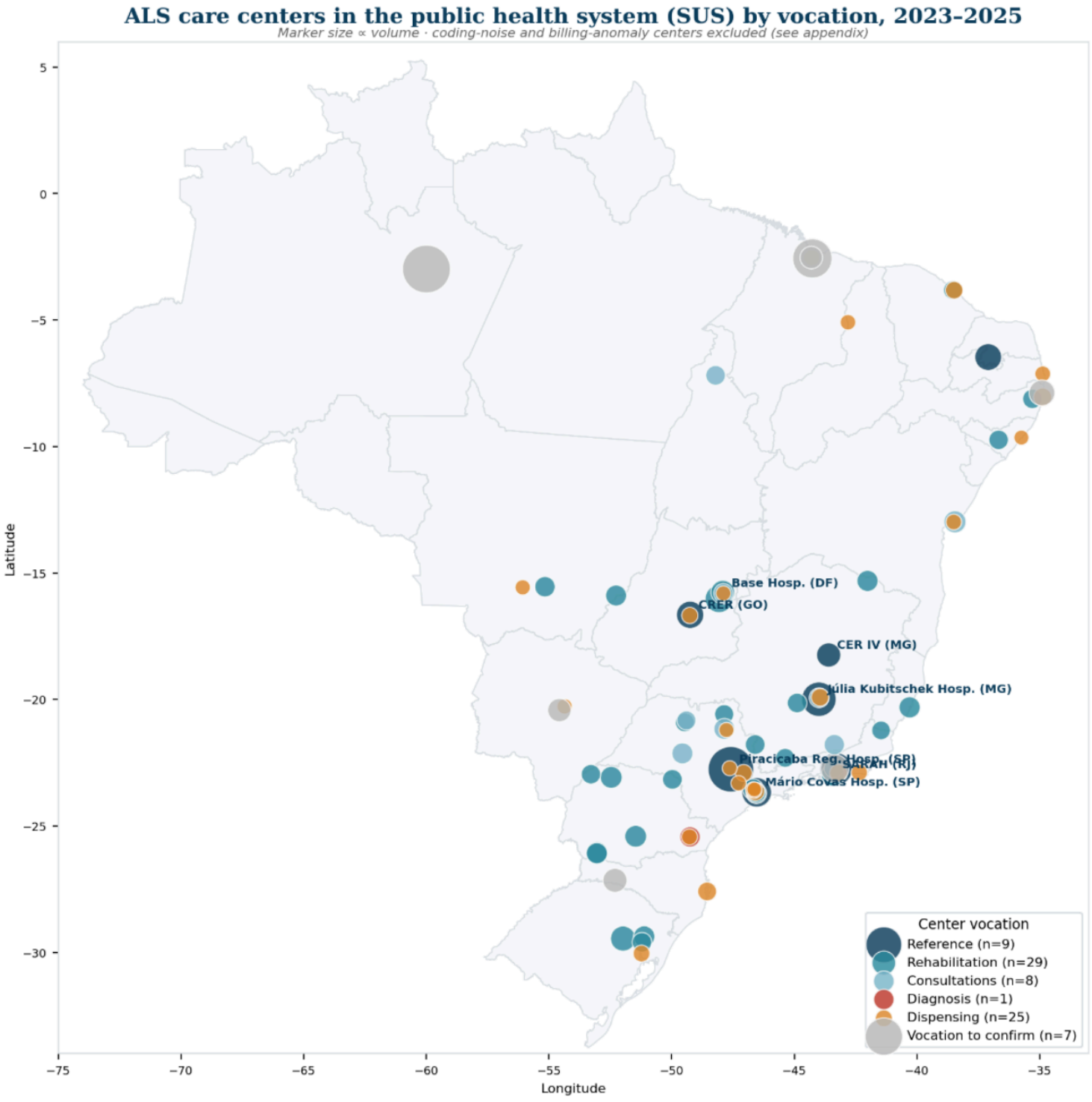


Figure 2

Geographic distribution and vocation of high-volume amyotrophic lateral sclerosis (ALS) care centers in Brazil. High-volume establishments were classified according to their predominant role in ALS care.

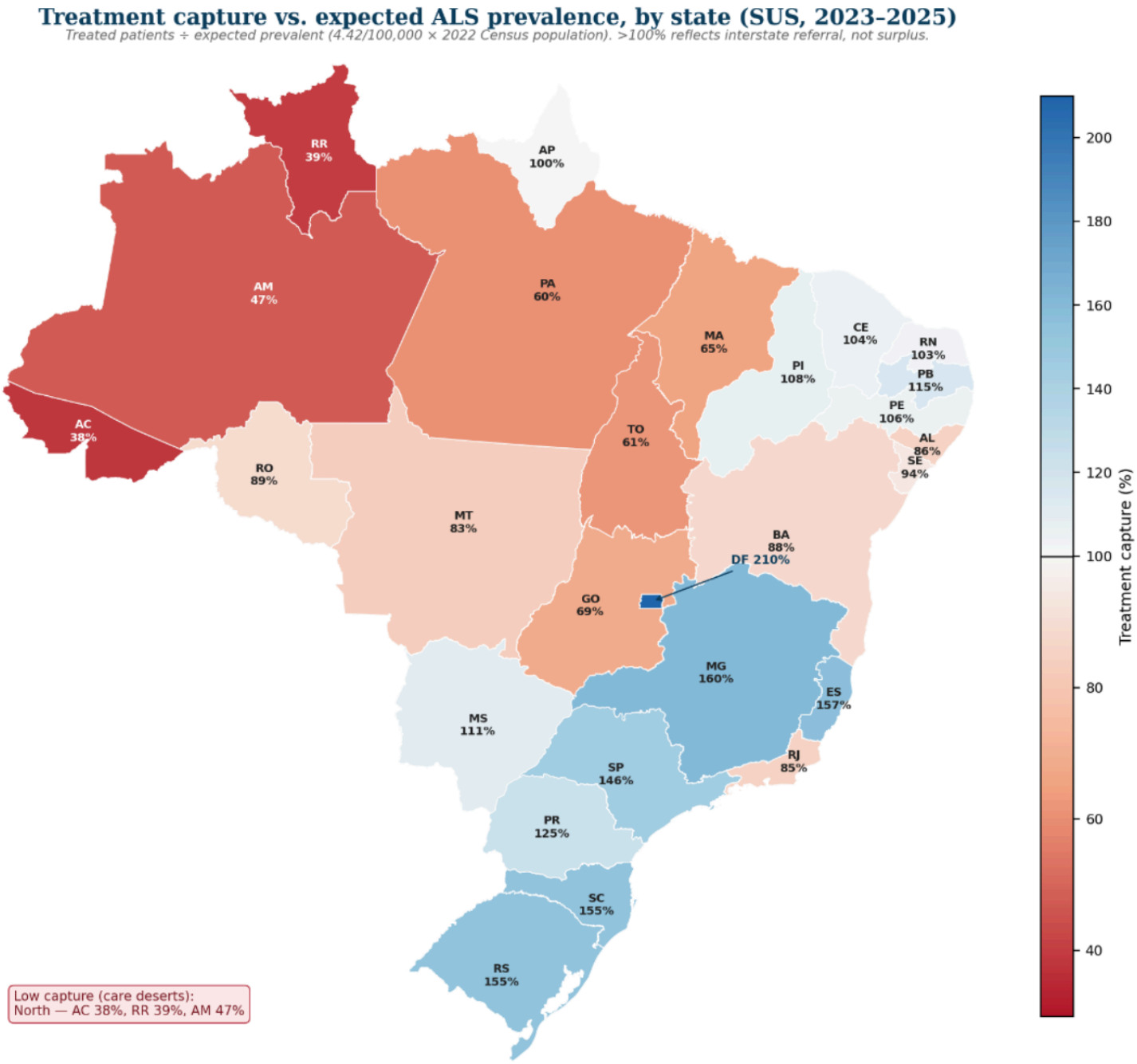


Figure 3

Relative treatment capture for amyotrophic lateral sclerosis (ALS) by state in Brazil. Relative treatment capture was calculated as the ratio of observed treated patients to the expected prevalent ALS cases based on population estimates.