

Travel Burden of Beta-Thalassemia Patients Receiving Red Blood Cell Transfusions in the Brazilian Public Healthcare System: A Real-World Study

RWD144

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Introduction

- B-thalassemia is a hereditary blood disorder characterized by defective production of beta-globin, leading to chronic anemia of varying severity caused by ineffective erythropoiesis.¹
- The prevalence of B-thalassemia differs by region, with higher occurrences in Mediterranean countries.² In Brazil there are 1,222 individuals registered with the condition in the Hemovida Informatized System, Web Hemoglobinopathies (covering all severity classifications and age groups).^{3,5}
- Regular Red Blood Cell Transfusions (RBCTs) are the primary supportive care for patients with Transfusion-Dependent B-thalassemia (B-TDT) and are usually required for life.^{3,4}
- However, regular RBCTs can lead to iron overload, which is associated with an increased risk of organ damage and death. Additionally, patients face the burden of frequent hospital visits, leading to a diminished quality of life.^{4,6,7}
- Given Brazil's size and limited data on patient characteristics and travel distances for RBCTs, this study aimed to evaluate utilization of ambulatory procedures and the travel burden of RBCTs for B-thalassemia patients in the Brazilian Public Healthcare System.

Methods

Ambulatory procedure utilization

- A retrospective observational review was conducted on ambulatory procedures related to B-thalassemia, International Classification of Diseases 10 (ICD-10) classification D56.1, registered from January 2015 to December 2023 in the Sistema de Informações Ambulatoriais do SUS (SIA-SUS).⁸
- The ambulatory procedures were quantified and described, along with their associated costs.
- Demographic characteristics of individual patients at first registry, including age and sex, were extracted from the records.

Travel burden related to RBCT

- Travel burden of B-thalassemia patients associated with RBCT was analyzed from recorded data.
- Distances in kilometers (km) and travel times by car (hours) between the municipality of residence and the municipality where the RBCT was performed were estimated using OpenStreetMap⁹, nationally and stratified by region.
- Continuous data were summarized using maximum, minimum, median, standard deviation (SD) and interquartile range (IQR), while categorical data were presented as numbers and percentages.
- All analyses were descriptive and performed using Python software, version 3.10.

Results

Ambulatory Procedures utilization and demographic characteristics

- Between 2015 and 2023, a total of 44,701 registries associated with ICD-10 D56.1 were imputed in SIA-SUS (149 different procedures).
- The demographic characteristics of patients at the first registry are summarized in Table 1.

Table 1. Demographic characteristics at first registry

Parameter	Total (n = 2,694)
Mean Age (SD) - years	24.63 (22.32)
Gender - n. (%)	
Male	1,286 (47.74)
Female	1,408 (52.27)

- The total expenditure in Brazilian Reais (BRL) related to ambulatory healthcare procedures for ICD D56.1 during the specified time period amounted to BRL 1.63 million.
- The ten most common ambulatory procedures, detailed in Table 2, collectively amounted to BRL 1.36 million.

Table 2. Ten most common approved ambulatory procedures

Code	Description	Procedures (n)	Sum of costs (BRL)
03.06.02.006-8	RBCT	13,873	286,143
02.12.01.002-6	Pre-transfusion exams I	11,933	296,343
02.12.01.003-4	Pre-transfusion Exams II	10,055	457,728
03.01.01.007-2	Medical consultation in specialized care	2,133	21,140
02.02.11.002-8	Molecular detection of mutation in hemoglobinopathies	892	55,968
02.02.02.038-0	Complete blood count	571	2,347
05.01.05.005-1	Identification of organ recipient	437	217,163
02.02.02.003-7	Reticulocyte count	432	1,179
02.02.01.038-4	Ferritin measurement	349	5,441
02.05.02.004-6	Total abdominal ultrasound	347	13,206

RBCT = Red Blood Cell Transfusion.

Travel burden related to RBCT

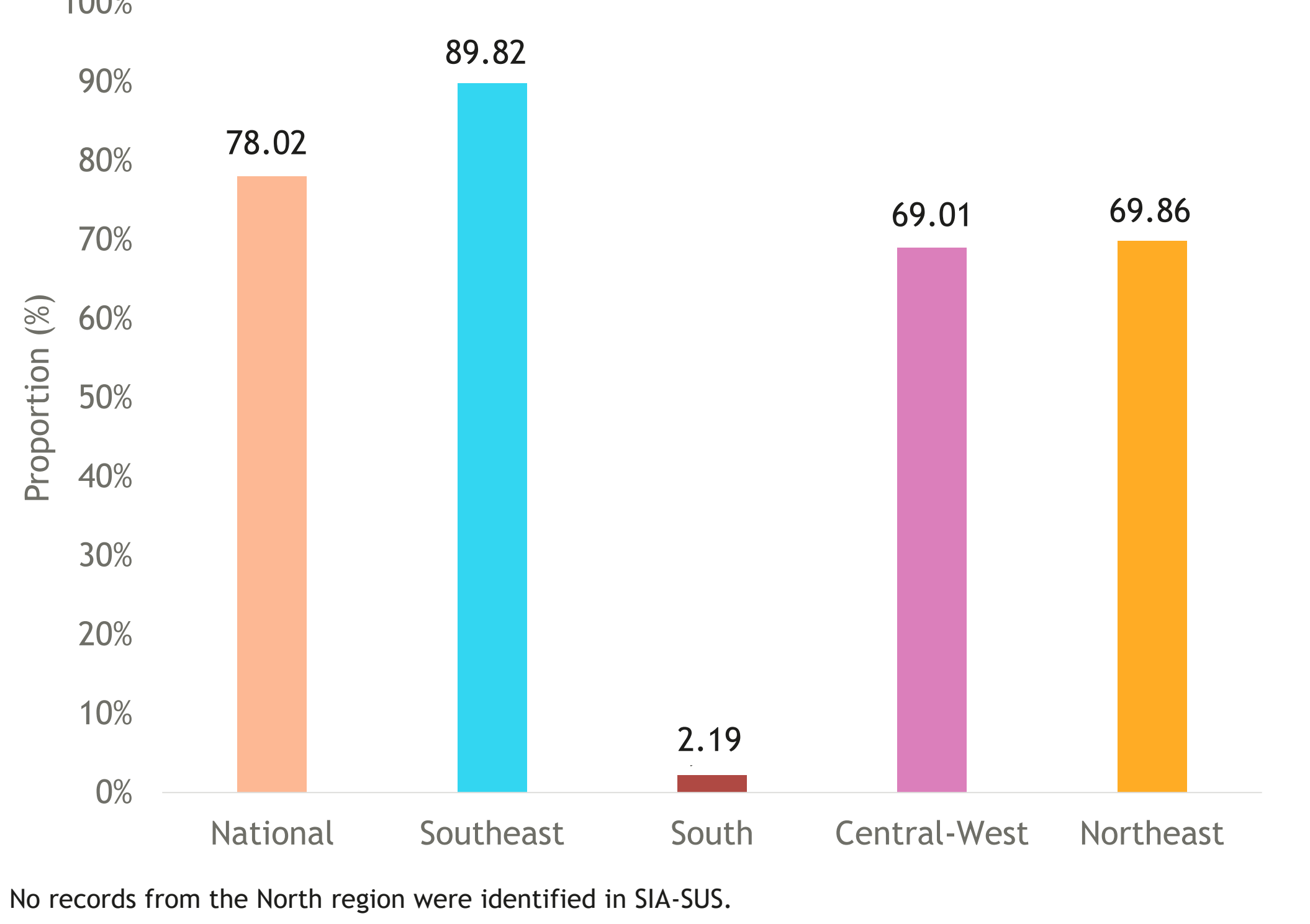
- The most frequently registered procedure was code 03.06.02.006-8 (RBCT), with 13,873 registries and an associated total cost of BRL 286,143.
- Table 3 presents the distribution of RBCT registries by region. There were no records from the North region.
- In 10,825 records (78.03%), the RBCT procedure was conducted in a municipality different from the patient's place of residence.
- Southeast (89.81%) and Northeast (69.76%) regions had the highest frequency of RBCT performed outside the municipality of patient's residence, whereas South (2.14%) had the lowest frequency (Figure 1).

Table 3. Number of RBCT procedure registries by region

Region	Total (n = 13,873)
Southeast	11,392
South	1,685
Central-West	224
Northeast	572
North	-

No records from the North region were identified in SIA-SUS.

Figure 1. Proportion of intermunicipal RBCT procedures



- The median (IQR) distance and car travel time for intermunicipal RBCT procedures were 78.98 (96.81) km and 1.07 (1.20) hours, respectively.
- The regions with the highest median distances (IQR) and times (IQR) were the South (348.81 km [127.81] and 4.67 h [1.36]) and the Central-West (87.29 km [242.16] and 1.21 h [3.78]) (Table 4 and Table 5).
- Northeast had the lowest medians (28.92 km [129.17] and 0.58 h [1.72]).

Table 4. Distance related to intermunicipal RBCT procedures

Region	Median (km)	Max (km)	Min (km)	IQR (km)
National	78.98	2,680.79	8.46	96.81
Southeast	78.98	2,680.79	8.46	96.81
South	348.81	632.83	20.53	127.81
Central-West	87.29	804.42	8.65	242.16
Northeast	28.92	682.05	18.78	129.17

Max: Maximum; Min = Minimum; IQR: Interquartile Range; km = kilometers; No records from the North region were identified in SIA-SUS.

Table 5. Car travel time related to intermunicipal RBCT procedures

Region	Median (h)	Max (h)	Min (h)	IQR (h)
National	1.07	34.23	0.17	1.20
Southeast	1.07	34.23	0.19	1.13
South	4.67	8.69	0.47	1.36
Central-West	1.21	11.52	0.17	3.78
Northeast	0.58	8.69	0.40	1.72

Max: Maximum; Min = Minimum; IQR: Interquartile Range; h = hours; No records from the North region were identified in SIA-SUS.

Conclusions

- This study analyzed utilization of health care ambulatory procedures for ICD D56.1 from from January 2015 to December 2023 using SIA-SUS data. A total of 44,701 records were identified amounting to BRL 1.63 million.
- RBCT was the most frequently recorded ambulatory procedure, and the Southeast region led in recorded RBCTs, highlighting its prominence in managing this condition in alignment with Brazil's population density and migration pattern.
- Notably, no records were found for the North region, indicating potential gaps in data recording.
- Our estimates are limited to SIA-SUS data, which may be incomplete if the reference center does not record the procedure. Moreover, we did not include inpatient RBCT procedures from the Sistema de Informações Hospitalares do SUS (SIH-SUS).
- The travel burden associated with RBCT was significant, with 78.02% of patients traveling outside their municipality for treatment.
- The South region reported the longest travel distances and times, despite having the lowest rate of intermunicipal RBCT procedures.
- The travel distance and time faced by B-thalassemia patients in Brazil requiring RBCT highlighted by this study, may indicate that patients may benefit from new therapeutic options that could reduce transfusion and mobility burdens for both patients and caregivers, ultimately enhancing their quality of life.

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