

# Solid organ transplantation in Brazil: a descriptive study of distribution and access inequalities across the Brazilian territory, 2001-2017\*

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## Abstract

**Objective:** to describe the distribution of solid organ transplants in Brazil, as well as information about the waiting list (demand) and origin of transplant patients by organ type and Federative Unit, from 2001 to 2017. **Methods:** this was a descriptive study using data from State Transplantation Centers, the Brazilian Organ Transplant Association, and the Brazilian National Health System Hospital Information System (SIH/SUS). **Results:** 153 transplant units were identified in 2017, with only 11.8% located in the Northern and Midwest regions; within the study period, 99,805 transplants were performed, ranging from 3,520 (2001) to 8,669 (2017); the highest number of transplants was concentrated in the Southern and Southeastern regions. **Conclusion:** there are inequalities in transplantation access, possibly due to lack of uniformity in service distribution.

**Keywords:** Organ Transplantation; Tissue and Organ Procurement; Health Equity; Health Services Accessibility; Epidemiology, Descriptive.

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## Introduction

Brazil is a world reference for transplants, with approximately 96% of transplant procedures funded by the Brazilian National Health System (SUS) in 2018 across the country.<sup>1,2</sup> There are two types of transplant: living donation, which is less common and only possible for some organs, such as kidneys; and deceased donation. In this second case, organ transplant is only considered when (i) the donor has been diagnosed as having brain death, (ii) the organ intended for donation is still functioning, (iii) family consent is obtained and, (iv) the recipient expressly agrees. This system became established with effect from official publication of Law No. 9434/97, later altered by Decree No. 9175/2017, which enabled the deployment of the centralized organ procurement and distribution system in Brazil. Within SUS, information about organ and tissue transplants is managed by the National Transplants System.<sup>3,4</sup>

*The proportion of the number of candidates waiting for a transplant exceeds the number of donors available which is insufficient to meet these needs, and this can represent unequal access*

Once need for transplant has been identified, the candidate is put on a single and exclusive waiting list for each organ. The main particularity of these waiting lists lies in establishing patient priority, considering not only order of joining the list, but also objective criteria related to medical conditions, in particular compatibility and disease severity.<sup>5</sup> Opting for a transplant as a therapeutic modality is a safe and efficacious form of treatment, given the optimization of the surgical procedure, its free of charge access, the advent of immunosuppressive drugs and increased knowledge about rejection and compatibility mechanisms.<sup>6,7</sup> However, transplant does not mean that the health problem is cured: for the rest of their life the recipient will be subject to transplant aftercare.

The amount of transplants performed, despite the statistics increasing every year, is substantially lower than the needs of the country's population. The proportion of the number of candidates waiting for a transplant exceeds the number of donors available which is insufficient to meet these needs,<sup>2,6,8,9</sup> and this can represent unequal access. This study looked at

social inequalities determining access to transplants, arising from occupying different positions in the social production structure and, consequently, the benefit of a service with scarce availability.<sup>10</sup>

Furthermore, when addressing transplant needs in Brazil, there are other associated factors to be taken into consideration. Standing out among these factors are the low notification rates of potential donors and the low rates of donation being realized, attributable to medical contraindications, family member refusals, the wish of potential donors not to donate while they are still alive, delay in diagnosing brain death, religious or cultural beliefs, as well as lack of knowledge and information about organ donation.<sup>9,11</sup> Recent Brazilian Transplant Registry data show a slight reduction in the rate of effective donors, which may be explained by the publication of the new Federal Council of Medicine resolution, which requires specific training for medical diagnosis of brain death.<sup>12</sup>

Brazilian literature on the subject of transplants is limited and lacks information about many issues related to the theme.<sup>2</sup> In view of the need for more studies about organ transplants in Brazil, the objective of this study was to present the distribution of solid organ transplants in the country, information about the waiting list (demand) for these organs and transplant patient origin.

## Methods

This is a descriptive study using data on solid organ transplants carried out in Brazil. The data sources on which it is based were the State Transplantation Centers and the Brazilian National Health System Hospital Information System (SIH/SUS),<sup>13</sup> by means of accessing the SUS Information Technology Department (DATASUS) website,<sup>14</sup> as well as the Brazilian Transplant Registry, based on statistics provided by the Brazilian Organ Transplant Association (ABTO).<sup>15</sup>

The data gathered from these sources, for each of the country's Federative Units (UF), refer to the time period comprising 2001-2017 and were retrieved by the same researcher in a standardized manner. This data was later checked by another member of the team involved. The data search was based on finding the variables correlated to the solid organs to be analyzed, followed by stratification by year and UF. These data were retrieved during October and November 2018, from each of the sources on the same day, in order to

avoid bias arising from probable system updates.

The variables relating to solid organ transplants, considering stratification by year, type of organ and UF, were: absolute frequency of the procedures performed; existing demand (waiting list) and absolute frequency of recorded SUS Hospital Admission Authorizations (AIH-SUS). Solid organs are understood to be the heart, lungs, kidneys, pancreas and liver. It should be emphasized that the patient waiting list is not defined by patient UF of residence, but rather by the UF of the transplant unit for which the patient is on the waiting list.

The data were organized using Excel, analyzed descriptively also using Excel and georeferenced using QGIS version 2.18.24, generating maps of weighted distribution per UF, for each analysis performed. When defining legend cut-off points, we used the criterion of equal intervals for the figures comparing maps with the same information for different years. We used the natural breaks criterion for the figures comparing maps containing different information or just one piece of information.

The country's transplant units were described by region and by UF, based on the data available on ABTO's Brazilian Transplant Registry.<sup>16</sup> This information was organized according to each institution's records at the Registry, by type of solid organ.

Data were included in the analysis relating to solid organ transplants, i.e. heart, lungs, kidneys, pancreas and liver, as well as pancreas transplants associated with kidney transplants (which may take place simultaneously), for each of the country's UFs. Presentation of this information enabled cumulative data on transplants in the period to be obtained, whereby the years 2001, 2009 and 2017 were selected in order to observe the temporal progression of transplants.

Following this, that data obtained from the State Transplantation Centers were compiled and organized by type of organ, so as to identify which UFs performed transplant procedures and their absolute frequency in the period. It should be highlighted that as there were considerably different numbers of transplant per type of solid organ, different scales needed to be used to present the findings. Therefore, for the purposes of comparison, data was retrieved on the population resident in the country in the year the most recent census was done (2010 Demographic Census).<sup>17</sup> In addition, the population data enabled us to estimate the transplant rate per 1 million inhabitants in Brazil, in the first and last year of observation.

The data relating to the solid organ waiting list, by UF, were retrieved from the Brazilian Transplant Registry available on ABTO's website<sup>14</sup> for the month of December 2017. In this case, the data was for total of all patients on the list, regardless of the organ to be transplanted.

The SUS Hospital Information System<sup>15</sup> was used because of the information it holds on surgical and hospital characteristics of transplant procedures, in order to identify the origin of the patients; here data were analyzed based on SUS Hospital Admission Authorizations (AIH), so as to identify the place of residence of transplant patients.

As the study used public data with no nominal identification of patients, the study project did not need to be submitted for analysis by a Research Ethics Committee.

## Results

Transplant center distribution in the UFs is presented in Table 1, together with the population estimated by the 2010 Demographic Census. Despite being present in all five regions of the Brazilian territory, a greater concentration of transplant units was found in the Southeastern and Southern regions, these being the only regions having units equipped to transplant all types of solid organs. Availability of transplant units in the period analyzed was lowest in the Northern Region, closely followed by the Midwest region; moreover there was not a single unit in these regions that performed lung and pancreas transplants. The states of Roraima, Amapá and Tocantins in the Northern region did not have an authorized transplant unit. The kidney was the solid organ with the highest number of active transplant units, totaling 129.

Growth in the number of transplants is shown in Figure 1. When comparing absolute national frequency between 2001 and 2017, an increase of around 150% was found, rising from 3,520 transplants in 2001 to 8,669 transplants in 2017. Considering the resident population, per 1 million inhabitants, there was a 108% increase in this rate, rising from 20.0 transplants per 1 million inhabitants in 2001 to 41.7 in 2017. Taking the entire period under analysis, 99,805 solid organ transplants were recorded.

According to spatial distribution, transplant growth per UF was most concentrated in the Southern and Southern regions, where 66.6% of the country's transplant units were found. São Paulo was the UF with the highest

**Table 1 – Distribution of transplant units per solid organ type, by region and Federative Unit (UF), Brazil, 2018**

Region (proportion (%) of the population)	Resident population / 2010 Census/ IBGE <sup>a</sup>	Transplant unit absolute and relative frequency (%)	Federative Unit (UF)	Transplant units informed by ABTO <sup>b</sup> per solid organ type (n)					Transplant unit (n) <sup>c</sup>	
				Heart	Liver	Pancreas	Pancreas + kidney	Lung		Kidney
<b>Midwest (7.3)</b>	<b>14,058,094</b>	<b>11 (7.2)</b>		<b>3</b>	<b>3</b>	<b>–</b>	<b>–</b>	<b>–</b>	<b>9</b>	<b>11</b>
	2,570,160		Federal District	1	2	–	–	–	4	5
	6,003,788		Goiás	2	1	–	–	–	4	5
	3,035,122		Mato Grosso	–	–	–	–	–	–	–
	2,449,024		Mato Grosso do Sul	–	–	–	–	–	1	1
<b>Northeast (27.8)</b>	<b>53,081,950</b>	<b>33 (21.6)</b>		<b>6</b>	<b>12</b>	<b>–</b>	<b>3</b>	<b>2</b>	<b>26</b>	<b>33</b>
	3,120,494		Alagoas	1	–	–	–	–	4	4
	14,016,906		Bahia	1	3	–	–	1	7	7
	8,452,381		Ceará	1	3	–	2	1	6	7
	6,574,789		Maranhão	–	1	–	–	–	1	1
	3,766,528		Paraíba	–	1	–	–	–	2	3
	8,796,448		Pernambuco	2	4	–	1	–	3	6
	3,118,360		Piauí	–	–	–	–	–	2	2
	3,168,027		Rio Grande do Norte	–	–	–	–	–	2	2
	2,068,017		Sergipe	1	–	–	–	–	1	1
<b>North (8.3)</b>	<b>15,864,454</b>	<b>7 (4.6)</b>		<b>–</b>	<b>1</b>	<b>–</b>	<b>–</b>	<b>–</b>	<b>7</b>	<b>7</b>
	733,559		Acre	–	1	–	–	–	1	1
	669,526		Amapá	–	–	–	–	–	–	–
	3,483,985		Amazonas	–	–	–	–	–	1	1
	7,581,051		Pará	–	–	–	–	–	4	4
	1,562,409		Rondônia	–	–	–	–	–	1	1
	450,479		Roraima	–	–	–	–	–	–	–
	1,383,445		Tocantins	–	–	–	–	–	–	–
<b>Southeast (42.1)</b>	<b>80,364,410</b>	<b>66 (43.1)</b>		<b>18</b>	<b>26</b>	<b>4</b>	<b>8</b>	<b>3</b>	<b>55</b>	<b>66</b>
	3,514,952		Espírito Santo	2	1	–	–	–	2	2
	19,597,330		Minas Gerais	3	7	–	2	–	19	20
	41,262,199		São Paulo	10	12	4	6	3	23	30
	15,989,929		Rio de Janeiro	3	6	–	–	–	11	14
<b>South (14.5)</b>	<b>17,762,891</b>	<b>36 (23.5)</b>		<b>9</b>	<b>13</b>	<b>3</b>	<b>3</b>	<b>2</b>	<b>30</b>	<b>36</b>
	10,444,526		Paraná	5	6	3	–	–	14	16
	10,693,929		Rio Grande do Sul	3	3	–	2	2	10	12
	6,248,436		Santa Catarina	1	4	–	1	–	6	8
<b>TOTAL</b>				<b>36</b>	<b>55</b>	<b>7</b>	<b>14</b>	<b>7</b>	<b>129</b>	<b>153</b>

a) IBGE: Brazilian Institute of Geography and Statistics.

b) ABTO: Brazilian Organ Transplant Association.

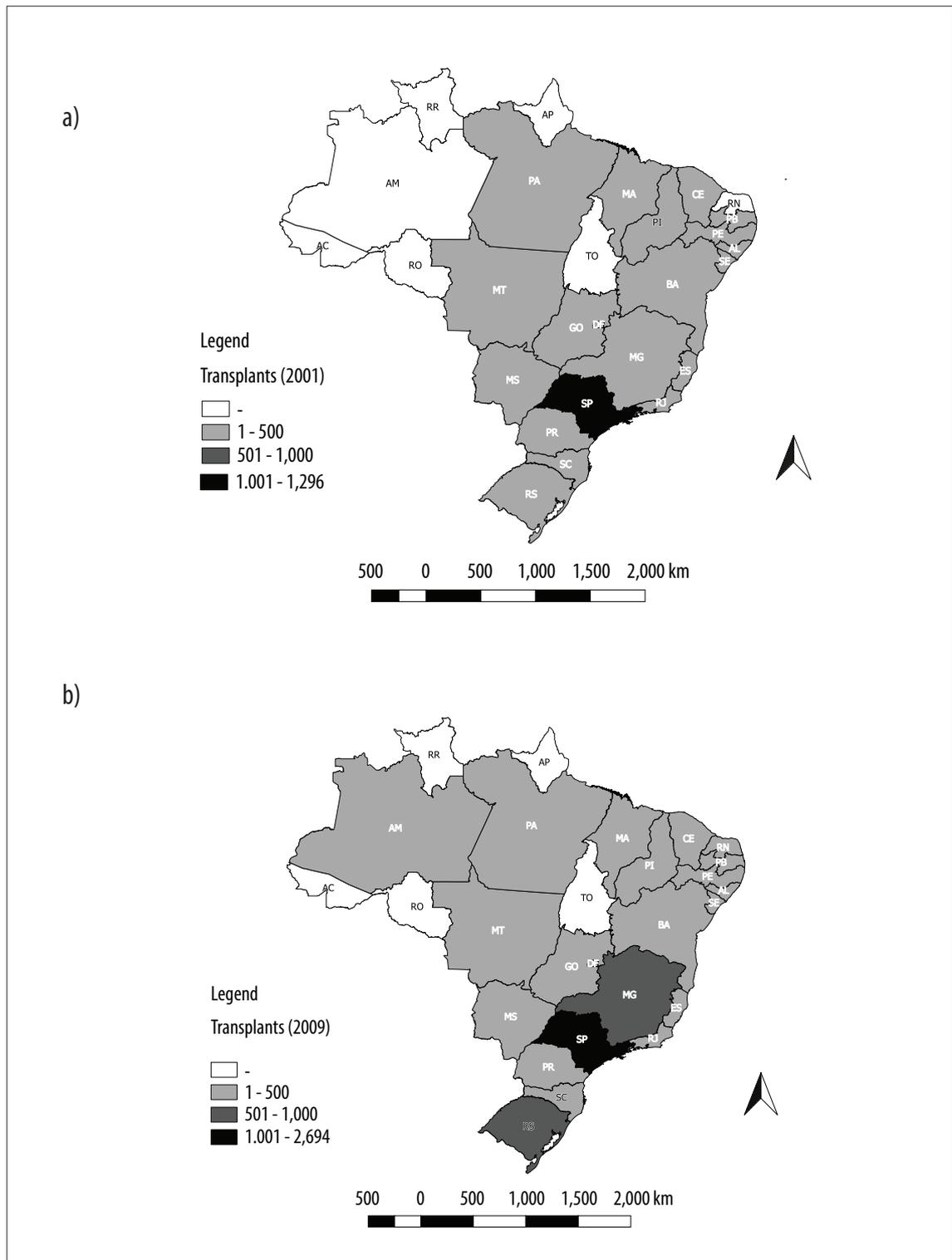
c) The number of transplant units does not necessarily consist of the total number of places that transplant solid organs, since the same unit may perform more than one type of transplant.

number of transplant units and the largest number of transplants performed.

The data on solid organ transplants performed between 2001 and 2017 pointed to kidneys transplants as being the most frequent (70,032; 70.2%), followed by liver transplants (22,078; 22.1%), heart transplants (3,793; 3.8%), pancreas associated with kidney transplants (2,119; 2.1%), lung transplants (1,014; 1.0%) and pancreas transplants on their own (878; 0.8%).

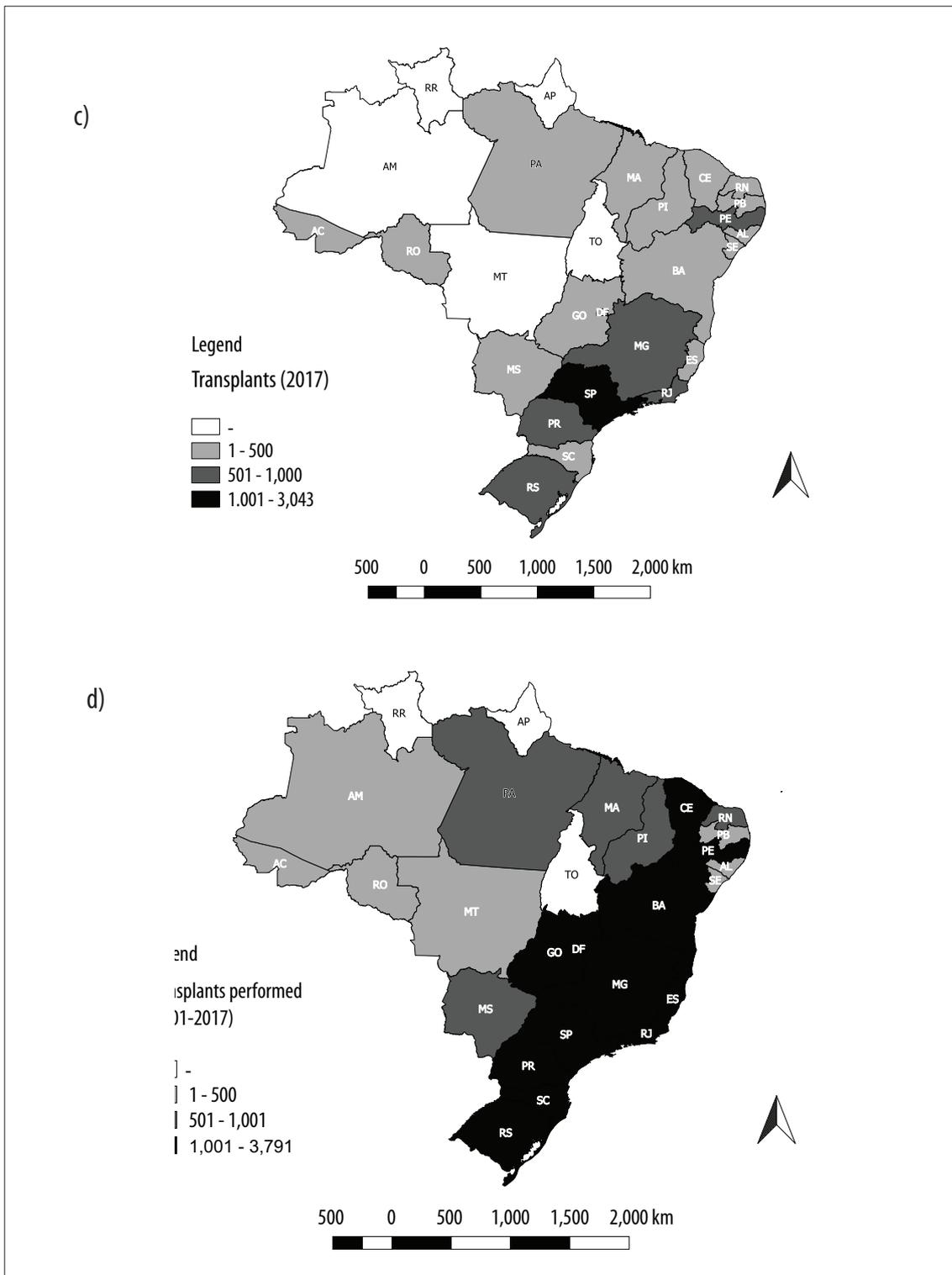
With regard to transplants according to organ transplanted (Figure 2), the Southern and Southeastern regions had the highest transplant frequencies for all organs analyzed, with kidney transplants occurring most throughout the national territory. The highest

transplant frequency in the Midwest region occurred in the Federal District where, apart from kidney transplants, liver and heart transplants also stood out. In the Northeastern region, kidney, liver, heart and pancreas associated with kidney transplants were most frequent in the states of Ceará and Pernambuco; while liver transplants were most frequent in the state of Bahia. In the Northern region, the state of Pará had the best kidney transplant indicator in the region, although it was low when compared to the UFs mentioned above. Acre is also worthy of mention as the Northern region's most active state with regard to liver transplants, with effect from 2004 when its transplant unit began operating.



*to be continued*

**Figure 1 – Distribution of solid organ transplants performed per Federative Unit (UF), Brazil, in 2001 (a), 2009 (b), 2017 (c) and cumulatively for the period 2001-2017 (d)**



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Distribution of active adult and pediatric patients on the waiting list for solid organ transplant in 2017 is shown in Figure 3. Once again the Southern and Southeastern regions had the biggest transplant waiting list. Five UFs – Mato Grosso, Amazonas, Roraima, Amapá and Tocantins – had no patients on the waiting list. The largest waiting list out of all solid organs was for kidney transplants, with 21,477 (90.2%) patients, taking the waiting list situation as at December 2017.

Following analysis of AIHs for transplant procedures, were we able to verify absolute transplant frequency per patient UF of residence (Figure 4). In this analysis, once again it was the Southern and Southern regions that had the highest concentration of transplant patients, along with Ceará and Pernambuco in the Northeast. The UFs with the lowest frequency of these procedures were Roraima, Amapá and Tocantins, respectively, with only 46, 47 and 96 transplants performed in people resident in these states between 2001 and 2017.

## Discussion

The results point to unequal transplant unit distribution between Brazil's geographic regions, being concentrated mainly in the South and Southeast where, consequently, the highest number of transplants was found. There was a threefold increase in the number of procedures performed in Brazil in the period studied, with São Paulo standing out as the UF with the biggest increase in transplants. Kidneys were the most frequently transplanted organ; practically the entire country has units authorized to perform kidney transplants, possibly because it is the organ with the biggest waiting list. Liver transplants came in second place, also with a high frequency of procedures, although distribution of units authorized to transplant this organ is lower across the country.

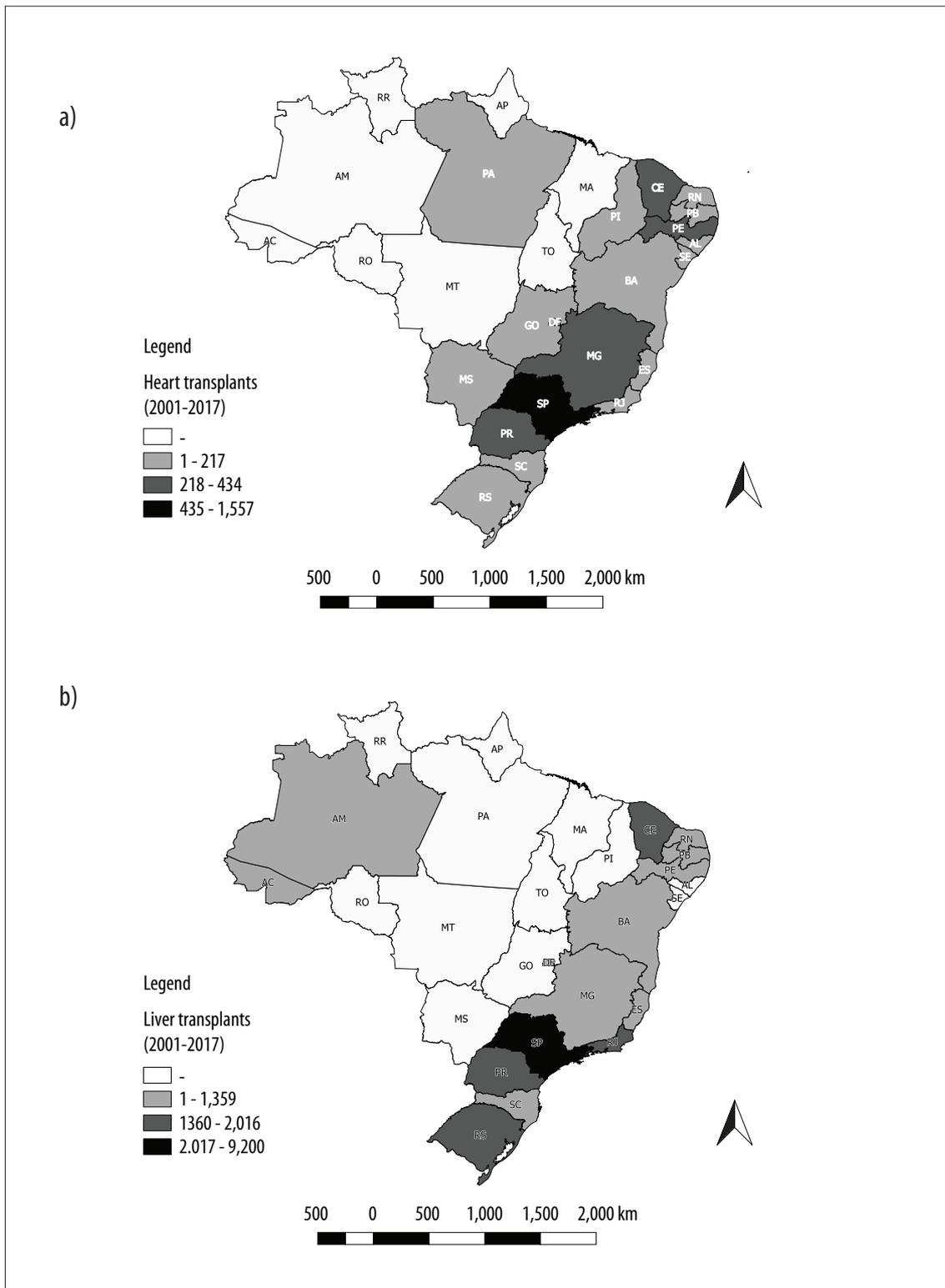
The number of transplants performed in Brazil increased between 2001 and 2017. This increase is due in part to the rise in the number of authorized transplant units. Even so, it can be seen that the majority of transplant units are concentrated in the Southern and Southeastern regions, demonstrating that the service is unequally distributed across the Brazilian territory.<sup>18,19</sup> Moreover, inequalities are clear when comparing UFs: São Paulo accounts for some ten thousand transplants, which is equivalent to total transplants performed in the 17 UFs with the lowest transplant rates.

Treatment of kidney failure with hemodialysis and peritoneal dialysis continues to stand out on the Brazilian scenario. Notwithstanding, from the cost point of view, kidney transplant is still advantageous in relation to other forms of treatment, despite accounting for only 6% of expenditure on treatment of chronic kidney disease. In recent years the North and Northeast regions have had a higher cumulative incidence rate of patients having dialysis on the SUS, in absolute numbers, reinforcing the social and economic relationship of chronic kidney disease. It is estimated that on average the current rate is 610 persons per 1 million inhabitants nationwide, varying from 473 in the North to 710 in the Midwest. According to the 2017 Brazilian Chronic Dialysis Survey, the annual mortality rate attributed to dialysis is 19.9%.<sup>20,21</sup>

Such unequal distribution results in certain problems related to accessing this form of treatment in some regions of the country. It is the case, for example, of people who live in the Northern region who face difficulties in accessing diagnosis and treatment for underlying diseases or even for hemodialysis, thus favoring the worsening of their health situation. Furthermore, the states of Mato Grosso, Amazonas, Roraima, Amapá and Tocantins had zero waiting lists when this manuscript was concluded, probably not because of lack of demand (patients needing treatment via transplants) but rather because of the fact that there are no authorized transplant services and, consequently, no candidates for transplants, thus resulting in underreporting of health needs. In those UFs, patients have to travel to other UFs to join a waiting list and then have access to transplants.

Having had a transplant requires a patient to live near to the transplant unit or have rapid transport available to get to it. Having a carer is also fundamental for treatment. As such, few patients can afford to live in another UF and have a carer at their disposal during the process of being included on a waiting list, the waiting time until the transplant and the time immediately after the transplant operation and discharge from hospital. At times this entire period can take months and often takes more than a year.

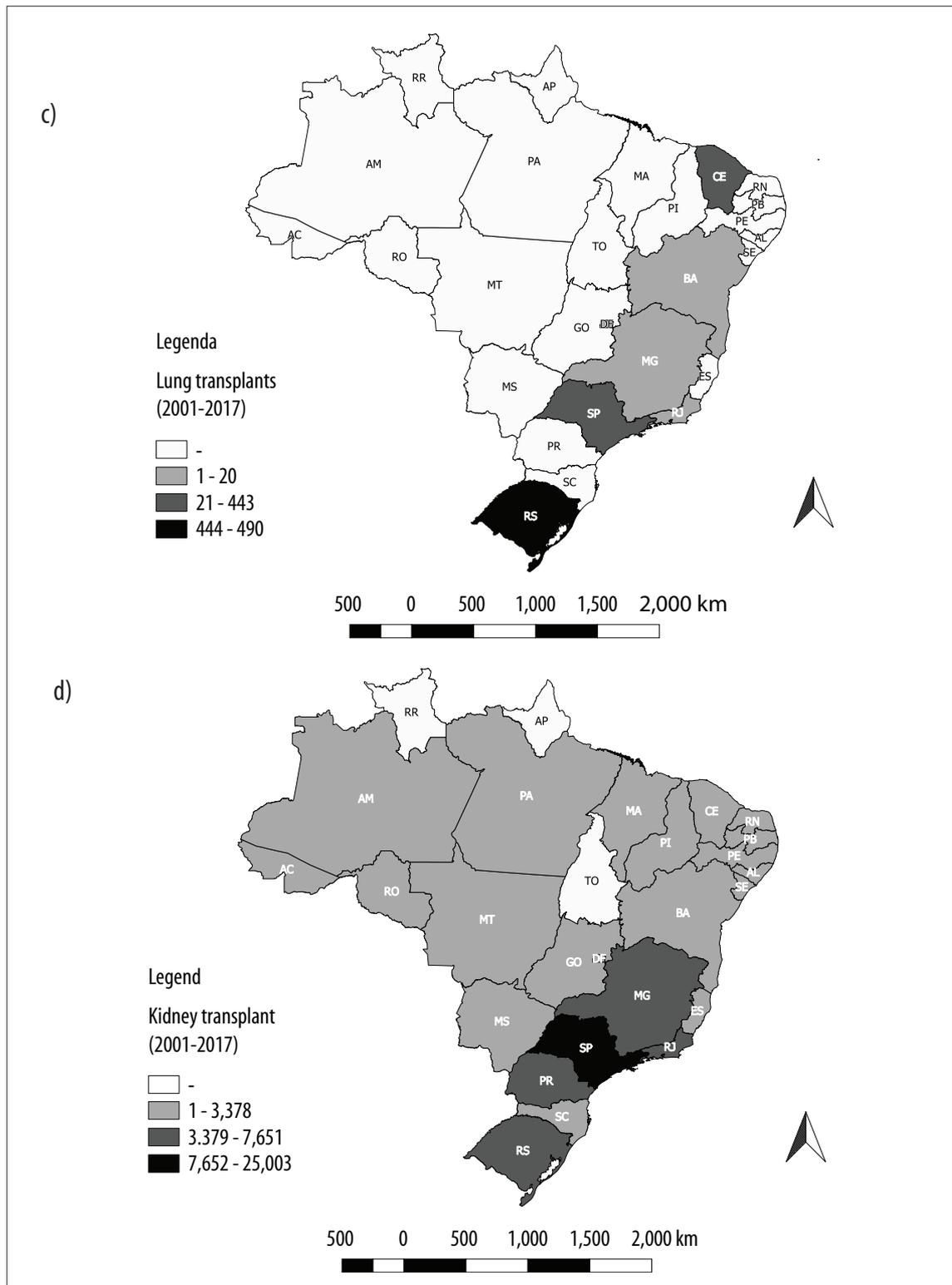
In other words, for priority to be given to a transplant, apart from the clinical aspects<sup>6,7</sup> mentioned earlier, financial status can enable people with higher incomes to have more access to this procedure, as identified by the concentration of transplant units in large cities and, in particular, greater access by people living in UFs



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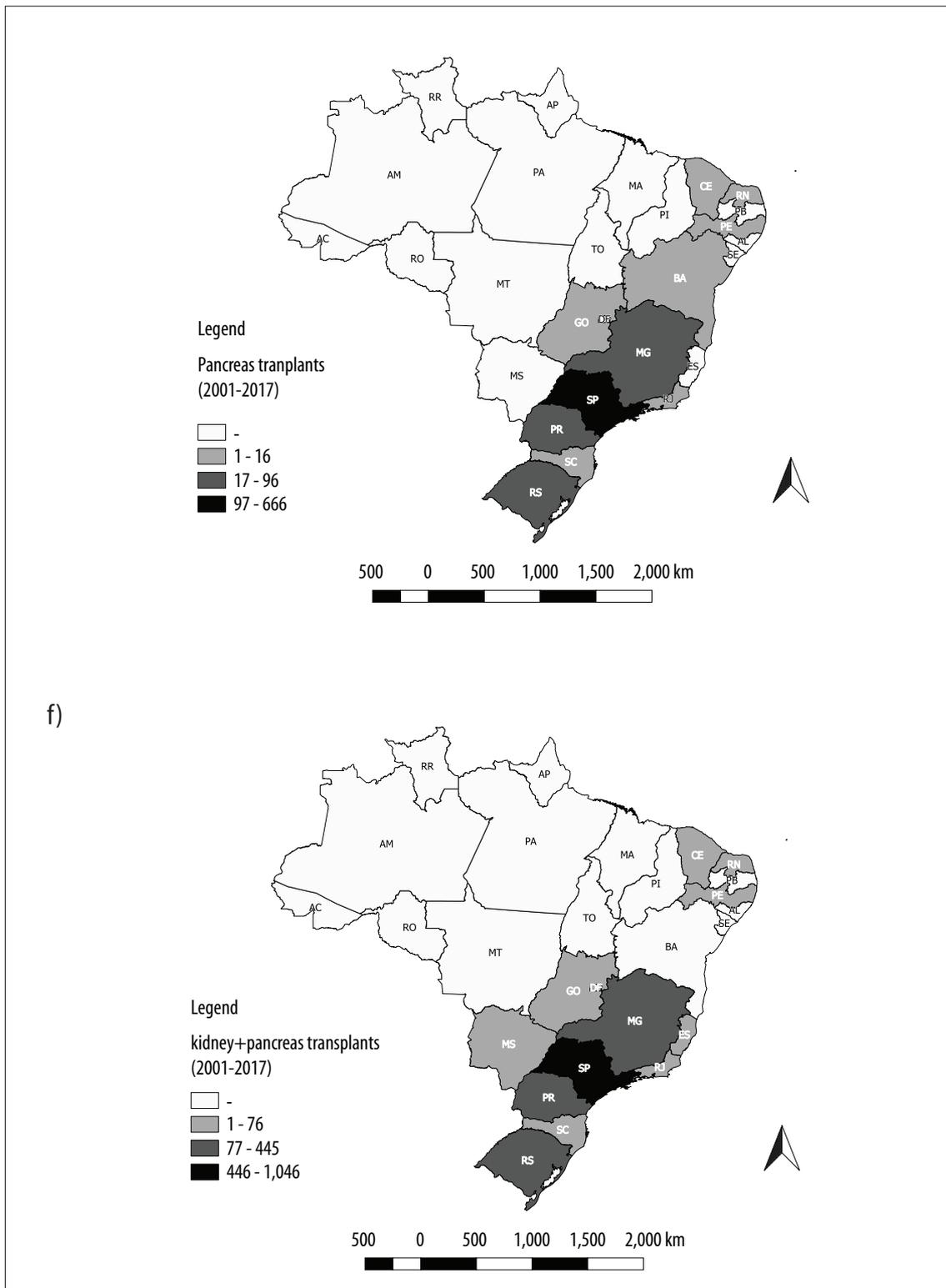
**Figure 2 – Distribution of solid organ transplants performed, by solid organ type [heart (a), liver (b), lung (c), kidney (d), pancreas (e) and rim + pancreas (f)], per Federative Unit (UF), Brazil, 2001-2017**

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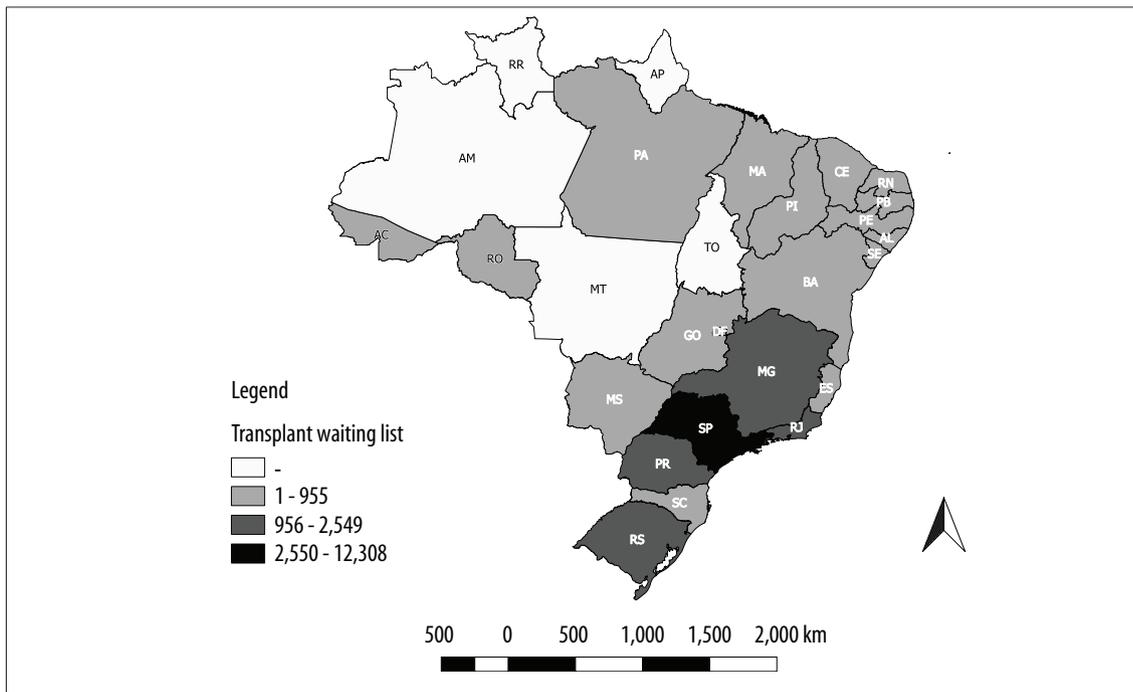


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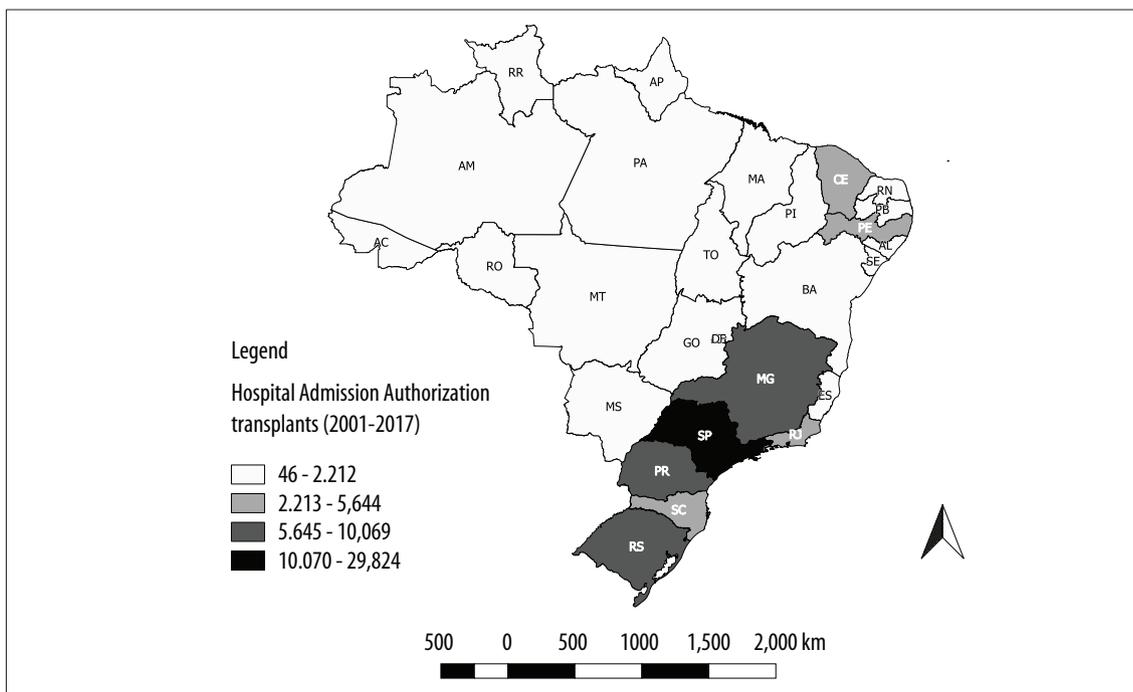
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**Figure 3 – Number of active patients on the solid organ transplant waiting list, per Federative Unit (UF), Brazil, December 2017**



**Figura 4 – Map of absolute frequency of Hospital Admission Authorizations (AIHs) for solid organ transplants, by place of residence and Federative Unit (UF), Brazil, 2001-2017**

in the South and Southeast. This is a hypothesis that suggests the need for further research.

As mentioned earlier, in UFs where transplant services are not available or are few, many patients find themselves obliged to migrate to other regions. A transplant patient needs outpatient clinic follow-up during the first three months following surgery, at least, and this is usually provided by the team of the transplant unit in question.<sup>22-24</sup> Due to these gaps in the service, there is difficulty in ensuring frequent follow-up of transplant patients in cities other than those in which they live, even after this initial period is over, given that many of them return to their UF of origin, where they will find health professionals unprepared for providing them with continuing care. Difficulty in accessing treatment and health services with the capacity to provide it, in the event of intercurrents, should also be taken into consideration, given the harm that can be caused to recovery and long-term treatment.

It must be highlighted that lack of transplant recipient access to a transplant unit or to specialized transplant teams can reduce their quality of life and their survival time, as well as causing difficulties with immunosuppression treatment and even death from loss of the transplanted organ.<sup>23</sup>

Another point worthy of mention in this study is the amount of kidney transplants performed in comparison with other organ transplants. A possible explanation for this finding may lie in the fact of the most common underlying diseases in modern society, such as arterial hypertension and diabetes, tending to unleash kidney problems, leading to greater probabilities of kidney failure and, consequently, greater need for kidney transplants.<sup>25-26</sup> According to Ribeiro & Schramm,<sup>27</sup> working to prevent disease and promote health is an important strategy for minimizing cases needing transplants. It is also noteworthy that deceased kidney donors can benefit up to two candidates, apart from the possibility of donation by someone who is alive, which also contributes to there being a high number of kidney transplants.

Larger waiting lists in the South and Southeast may contribute to the greater number of Hospital Admission Authorizations for transplants in the UFs in these regions. Moreover, transplant procedures are

more likely to occur in the South/Southeast than in the North/Northeast.<sup>3</sup>

This study was not able to access data about donors and, therefore, association was not identified between organ supply and demand. In addition, information about recipient place of residence did not enable analysis of the journey made to get health care. As such, it was not possible to estimate with precision transplant rates per 1 million inhabitants per UF, due to patient migration. For example, the Federal District has high transplant rates in relation to its population, because many patients originate from other UFs. With regard to the numbers of transplant units, a further limitation found by this study was the unavailability of information about units effectively in operation.

Through this study it was possible to identify how solid organ transplant operations are distributed across Brazil, the transplant waiting list situation and progress made with this procedure by SUS over time. The findings point to regional inequalities, principally when comparing the country's main state capitals with the less developed UFs, possibly arising from multiple causes. We hope that this study will contribute to greater understanding of the Brazilian organ donation and transplant scenario, in the sense of mapping and identifying the main gaps in transplant distribution and encouraging the performance of more transplant procedures, principally in the Northern region UFs.

The results and analyses present conclusively open perspectives for future studies, ranging from the costs of the procedures implicit to this kind of treatment to, above all, its social and health determinants, so as to shed light on the disparities present in Brazilian solid organ transplant reality.

### Authors' contributions

Soares LSS, Brito ES, Magedanz L and Galato D contributed to the conception of the study, data analysis and interpretation and drafting the manuscript. Brito ES, Magedanz L and França FA took part in data gathering and analysis. França FA and Araújo WN contributed to drafting the manuscript. All the authors have approved the final version and take responsibility for all aspects of the work, guaranteeing its accuracy and integrity.

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