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# Availability and barriers to access post-stroke rehabilitation in Latin America

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### ABSTRACT

Objectives: To describe the availability and barriers to access post-stroke rehabilitation services in Latin America. *Materials and methods*: We conducted a multi-national survey in Latin American countries. The survey consisted of three sections: (1) the national state of post-stroke rehabilitation; (2) the local state of post-stroke rehabilitation; and (3) the coverage and financing of post-stroke services. Stroke leaders from the surveyed countries were involved in developing and disseminating the survey.

Results: 261 responses were collected from 17 countries. The mean age of respondents was  $42.4 \pm 10.1$  years, and 139 (54.5 %) of the respondents were male. National clinical guidelines for post-stroke rehabilitation were reported by 67 (25.7 %) of the respondents. However, there were discrepancies between respondents within the same country. Stroke units, physiotherapy, occupational therapy, speech therapy, and neuropsychological therapy services were less common in public than private settings. The main barriers for inpatient and outpatient services included limited rehabilitation facilities, coverage, and rehabilitation personnel. The main source of financing for the inpatient and outpatient services was the national health insurance, followed by out-of-pocket payments. Private and out-of-pocket costs were more frequently reported in outpatient services.

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Conclusions: Post-stroke rehabilitation services in Latin American countries are restricted due to a lack of coverage by the public health system and private insurers, human resources, and financial aid. Public settings offer fewer post-stroke rehabilitation services compared to private settings. Developing consensus guidelines, increasing coverage, and using innovative approaches to deliver post-stroke rehabilitation is paramount to increase access without posing a financial burden.

## Introduction

Stroke is a leading cause of morbidity and mortality worldwide. It is estimated that over 143 million years of healthy life are lost each year due to stroke-related death and disability, which will continue to increase over the coming decades. <sup>1,2</sup> Latin America is one of the regions with the highest burden of stroke. Prevalence studies estimated an overall crude prevalence of more than 3,000 cases per 100,000 people. <sup>3</sup> A community-based study from Chile reported that 1 in 5 patients remain burdened with a disability 6 months after stroke. <sup>4</sup>

Improvements in the quality and access to acute stroke care mean there is now a higher number of stroke survivors.  $^{5,6}$  In Latin America, the Years Lived with Disability (YLDs) due to stroke have risen over 50 % from 2000 to 2019. As acute treatment expands and continues to innovate, the burden on post-stroke rehabilitation services will follow. The direct and indirect (i.e., loss of income) cost of stroke services – including rehabilitation – will increase from US\$891 billion per year in 2017 to over \$2 trillion by 2050.  $^8$ 

The increasing burden of stroke in Latin America has driven regional initiatives to improve stroke care. One of the major initiatives is the Declaration of Gramado in 2018, aimed to improve stroke prevention, treatment, and rehabilitation. In 2020, an evaluation of the progress since 2018 evidenced higher stroke awareness campaigns and an increase in stroke centres. While these achievements are to be celebrated, the study by Sheila et al also revealed a major gap in the knowledge about rehabilitation services after stroke. Therefore, this study aims to describe the availability and barriers to access post-stroke rehabilitation services in Latin America.

## Methods

The study was conducted between March and September 2023. An international scientific committee was formed, consisting of stroke leaders in Latin American countries (including ALATAC)<sup>11</sup> and stroke researchers in England. The scientific committee held three meetings during this period to discuss the content of an electronic survey to explore the state of post-stroke rehabilitation services in Latin America. First, a questionnaire was developed based on a previous study exploring barriers to stroke care, adapting it to the context of post-stroke rehabilitation. 12 The questionnaire was then reviewed by the scientific committee to ensure questions were adapted to the Latin American context. This process was repeated twice. Agreement on the survey's content was achieved via consensus and the English version of the survey was translated and validated by Spanish and Portuguese native speakers. A pilot study was conducted in June 2023 to identify errors or unclear questions. The amended survey in English is available in Supplementary Material 1.

The survey was organised into three main sections. The first section inquired about the availability of guidelines on post-stroke rehabilitation in each country, including public-private differences in the availability of stroke units and rehabilitation modalities (physiotherapy, speech therapy, occupational therapy, and cognitive therapy). Furthermore, this section assessed perceived barriers to accessing inpatient and outpatient post-stroke rehabilitation. Barriers were queried using a Likert-type scale and included the availability of guidelines, personnel, infrastructure (i.e., rehabilitation centres), and awareness of post-stroke rehabilitation. An open-ended question was included to allow participants to mention barriers not included by the scientific committee.

The second section of the survey explored the services offered in the hospitals in which the respondents conduct their clinical practice, including hospital characteristics (i.e., number of beds, types of rehabilitation offered, access to mental health support and psychiatrists). Double practice is common in Latin American countries. Therefore, participants were asked to provide details of up to two hospitals, enabling us to capture information from more settings. The final part of the questionnaire explored the coverage and financing of the different rehabilitation modalities and asked if botulinic toxin for post-stroke care is publicly financed.

The electronic survey was sent to healthcare personnel involved in stroke care (i.e., nurses, doctors, physiotherapists). We estimated around 750 professionals could be contacted through ALATAC's social media groups and local stroke organizations. Using a 95 % confidence level and 5 % margin error, we calculated a sample size of 255 participants. We aimed for a higher sample size to consider potential incomplete or missed surveys. Moreover, based on expert opinion, we decided to recruit answers from at least three different cities per country. This avoided collecting information only from capital cities, where developed stroke care centres are more commonly located. We identified local leaders of 17 countries who electronically spread the survey in their countries through local stroke organizations.

Participants were asked to complete the questionnaire voluntarily and informed they could withdraw at any time. The information remained anonymous and confidential and was only accessed by one member (AGA) of the research team. Ethical approval was waived by the Ethics Committee at the University of Bradford.

## Statistical analysis

A descriptive analysis of the participants' responses was conducted. Frequencies are presented as proportions and numerical variables as mean ( $\pm$  standard deviation) or median (interquartile range). The analysis began with information at the national level. Responses from the Likert-type questions were analysed based on the severity level (i.e., partially or totally agree vs partially or totally disagree). The examination of the national data was followed by an analysis of the individual hospitals. Each hospital was considered as a unit of analysis, thus leading to a larger sample than the number of individuals. Comparisons between categorical variables were made using either Chi-square or Fisher's test, according to the sample size. A p value of <0.05 was considered significant. Data analysis was performed using SPSS software for Windows, version 23 (SPSS, Inc., Chicago, IL, USA).

## Results

A total of 261 responses were collected between June and September 2023 (Table 1). The respondents were from 98 cities distributed throughout 17 countries. The number of cities represented per country varied from 2 (Ecuador, El Salvador, Paraguay) to 14 (Mexico). The mean age of respondents was  $42.4 \pm 10.1$  years, and 139 (54.5%) of the respondents were male. The two main respondents were neurologists 97 (37.2%) and stroke physicians 67 (25.7%). Physiotherapists, occupational therapists, and speech language therapists accounted for 23 (8.7%) of the respondents. Respondents had an average of  $13 \pm 9.7$  years working in their current health systems. 131 (50.2%) respondents worked at a single hospital site, 82 (31.4%) respondents worked at two hospital sites, and 48 (18.4%) worked at more than two hospital sites.

**Table 1**Characteristics of respondents.

Variable	N=261
Age (years)	$42.4\pm10.1$
Male sex; n (%)	139 (54.5 %)
Training background	
General neurologist	97 (37.2 %)
Stroke physicians	67 (25.7 %)
Physician with rehabilitation specialty	31 (11.9 %)
Physician with other specialty	41 (15.7 %)
Nurse	2 (0.8 %)
Physiotherapist	16 (6.1 %)
Occupational therapist	4 (1.5 %)
Speech language therapist	3 (1.1 %)
Countries	
Argentina	19 (7.3 %)
Bolivia	7 (2.7 %)
Brazil	11 (4.2 %)
Chile	15 (5.7 %)
Colombia	25 (9.6 %)
Costa Rica	17 (6.5 %)
Dominican Republic	8 (3.1 %)
Ecuador	4 (1.5 %)
El Salvador	9 (3.4 %)
Guatemala	38 (14.6 %)
Honduras	16 (6.1 %)
Mexico	28 (10.7 %)
Nicaragua	6 (2.3 %)
Panama	16 (6.1 %)
Paraguay	5 (1.9 %)
Peru	17 (6.5 %)
Uruguay	20 (7.7 %)
Years of practice in the current health system	$13 \pm 9.7$
Number of hospital(s) in which participants work	
1	131 (50.2 %)
2	82 (31.4 %)
More than 2	48 (18.4 %)

Access to national clinical guidelines for post-stroke rehabilitation were reported by 67 (25.7 %) of the respondents. However, there were discrepancies between respondents within the same country. Stroke

units (13 (5 %) vs 44 (16.9 %); p<0.001), physiotherapy (106 (40.6 %) vs 159 (60.9 %); p<0.001) occupational therapy (37 (14.2 %) vs 74 (28.4 %); p<0.001), speech therapy (33 (12.6 %) vs (83 (31.8 %); p<0.001), and neuropsychological therapy services (17 (6.5 %) vs (47 (18 %); p<0.001) were less common in public than in private settings.

The reported barriers to accessing inpatient and outpatient post-stroke rehabilitation services are shown in Fig. 1. For inpatient rehabilitation, the main barriers in the public sector are the lack of infrastructure, the lack of coverage by the national health system, and the lack of rehabilitation personnel. In the private sector the main barriers are the lack of rehabilitation personnel and coverage by private insurers. For outpatient rehabilitation, the main barriers in the public sector are the distance to rehabilitation facilities, the lack of rehabilitation personnel, and the lack of infrastructure. In the private sector, the main barriers are the lack of coverage by private insurers, distance to rehabilitation facilities, and the lack of rehabilitation personnel. The differences between the public and private sectors were statistically significant (p<0.001) regarding all barriers, with a higher share of participants reporting more barriers in the public sector.

Open ended answers for inpatient barriers included limited number of sessions covered by public and private insurers, long waiting lists, and lack of multidisciplinary approaches. For outpatient services, respondents mentioned the same barriers and added lack of training for carers and adaptation of residences to patient's needs.

Practice in 391 hospitals was surveyed. Most of the hospitals were public teaching hospitals 175 (44.8 %), followed by private teaching 89 (22.8 %) and private non-teaching hospitals 88 (22.5 %). Around half 173 (44 %) of the hospitals had between 101 and 500 beds, and 123 (31.5 %) had dedicated stroke units with a median of 5 beds (IQR 3–10.25). Despite the majority of the patients from the reporting hospitals having access to mental health services, a notable proportion 107 (27.4 %) did not. Similarly, in 1 in 5 hospitals, patients had no access to either a psychologist or psychiatrist. In 122 (31.2 %) of the hospitals, there was no access to a physiatrist. No differences were found in the availability of rehabilitation services between private and public hospitals (Table 2). Only mental health assessments were reported to be

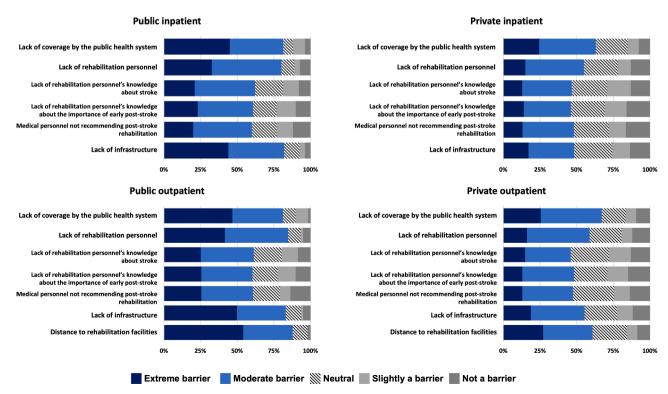


Fig. 1. Barriers to access post-stroke rehabilitation services in Latin American countries.

higher in private hospitals (30 (15.2 %) vs 51 (28 %), p=0.022).

The financing of post-stroke rehabilitation services was diverse (Fig. 2). The main source of financing for the inpatient and outpatient services was the national health insurance, followed by OOP payments. Private and OOP payments were more frequently reported in outpatient services. Lastly, 109 (41.8 %) respondents reported botulinum toxin for post-stroke rehabilitation was financed by the public health system.

#### Discussion

Our study describes for the first time the availability and barriers of post-stroke rehabilitation in Latin American countries. At the national level, the respondents identified an absence of national clinical guidelines for post-stroke rehabilitation relevant to the practitioner's setting of practice. However, the discrepancies within countries suggest a lack of awareness of post-stroke rehabilitation guidelines or that respondents referred to national stroke guidelines that might include post-stroke care, as the latter are widely available. <sup>10</sup> Establishing a common route through national clinical guidelines is essential to ensuring that patients receive a standard pathway of care. <sup>13</sup> Clinical guidelines have been shown to increase compliance to care, <sup>14</sup> especially when these are developed with a person-centred approach and involve the personnel who will follow the guidelines. <sup>15,16</sup>

The differences in services' availability between the public and private sectors is stark. The private sector has a great prevalence in some Latin American countries and has increased in recent years. <sup>17</sup> Patients treated in public hospitals report worse outcomes than those in private settings. <sup>18,19</sup> However, rather than reducing private services, public institutions can collaborate with their private counterparts to expand access to post-stroke rehabilitation services. In the United States, for example, the public-private partnerships (PPP) 'Million Hearts' increased stroke awareness and implemented blood pressure screening campaigns, preventing 135,000 cardiovascular events (including stroke) and saving US\$5.6 billion in direct healthcare costs. <sup>20</sup> Latin American countries can leverage the growing private healthcare sector and collaborate to increase access to high-quality post-stroke care.

The main barriers identified by this survey in the access to post-stroke rehabilitation services were related to the coverage and availability of human resources and infrastructure. Limiting access to post-stroke rehabilitation leads to worse long-term health outcomes. Equally detrimentally, it leads to further expenses that severely impact patients from lower income quintiles. Another main barrier is the limited number of rehabilitation personnel. The number of physiotherapists is heterogeneous in the region, ranging from 18.5 per 10,000 in Chile to 0.2 per 10,000 in Dominican Republic in 2022. The situation with occupational therapists is worse, especially in comparison with other parts of the world. For instance, Canada and the United States have over 4 occupational therapists per 10,000, while Latin American countries with available data reported less than 1 per 10,000.

Respondents also noted a lack of facilities available to provide post-stroke rehabilitation. Comprehensive stroke centres in Latin America tend to be located in capital cities. <sup>23</sup> The concentration of rehabilitation centres in urban areas, often far from patients' homes, leads to higher costs, which in turn exacerbates inequities in access. The higher costs are not only due to transportation to rehabilitation centres, but also cover domiciliary visits and adapting patients' homes to their needs. A study conducted by Silva-Sieger et al in Colombia reported that a mean of 570.83 USD (over twice the minimum monthly wage) was spent out-of-pocket adapting patients' homes. <sup>24</sup>

Physical and human resources constraints in the region call for innovations to increase patients' access to rehabilitation services. While increasing the number of professionals would contribute to solving the problem, training will take considerable time. The use of telemedicine and specialised software for rehabilitation is a potential solution, especially in the wake of the increasing number of telemedicine networks created during the COVID-19 pandemic.<sup>25</sup> Successful examples can serve as a reference to Latin American countries. For instance, in Denmark, older adults have access to a software platform (DigiRehab ©) that provides videos and records users' progress based on standard metrics, leading to a more efficient use of human resources.<sup>26</sup>

The information about the local hospitals did not reflect the differences expressed at the national level. This lack of contrast can be attributed to the type of hospitals in which the majority of the respondents worked. Over two thirds reported working in public or private teaching hospitals, with the capacity to offer comprehensive stroke services. Moreover, mental health services were more commonly available in private than public settings. Around a third of stroke survivors experience anxiety and depression after stroke. Also, suicide ideation has been reported to be 12 % after stroke, with around 6 % reporting suicide planning.<sup>27</sup> Younger stroke survivors (<50 years) exhibit higher risk of suicide compared to older survivors. <sup>28</sup> The limited number of hospitals reporting mental health assessments after stroke indicates the need for holistic evaluations. This is particularly important, as global prevalence of mental ill health burden is expected to increase.<sup>29</sup> Peer-support networks are an efficient and effective way of reducing this burden without adding pressure to health systems. A study by Christensen et al showed that establishing peer-support networks can improve the mental health and post-stroke recovery of patients.

Lastly, the financial coverage of post-stroke rehabilitation services was reported to be mainly from the national health insurers (NHI), with a significant contribution of OOP payments. The limited number of covered sessions might explain the high reliance on OOP payments. Relying heavily on OOP payments and private funding will lead to further stroke inequalities, as well as the risk of catastrophic expenditures among the poorest income quintiles and those living in rural areas. <sup>31</sup>

Our survey has strengths that merit comment. We surveyed a large sample from multiple Latin American countries. We also worked with

**Table 2**Availability of inpatient and outpatient post-stroke services in hospitals of practice.

Service offered	public hospitals h		Inpatient, private hospitals N=187		P value	Outpatient, public hospitals N=204	Outpatient, private hospitals N=187	P value
	All	Only SU	All	Only SU				
Physiotherapy services	147	22	141	14	0.522	157	140	0.217
	(72.1 %)	(10.8 %)	(75.4 %)	(7.5 %)		(77 %)	(74.9 %)	
Occupational therapy services	83	30	73	16	0.109	113	90	0.151
	(40.7 %)	(14.7 %)	(39 %)	(8.6 %)		(55.4 %)	(48.1 %)	
Speech therapy services	95	28	98	20	0.448	121	118	0.487
	(46.6 %)	(13.7%)	(52.4 %)	(10.7 %)		(59.3 %)	(63.1 %)	
Neuropsychological therapy services	53	27	59	15	0.171	84	83	0.489
	(26 %)	(13.2 %)	(31.6 %)	(8 %)		(41.2 %)	(44.4 %)	
Mental health assessment	30 (15.2 %)		51 (28 %)		0.022*		•	

<sup>\*</sup> p<0.05; SU: Stroke Unit.

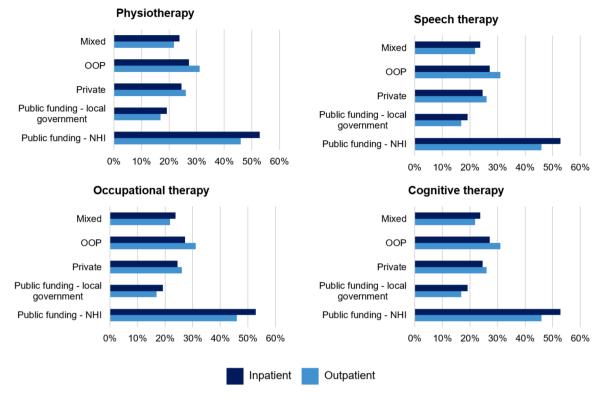


Fig. 2. Reported financing sources for physiotherapy, speech therapy, occupational therapy, and cognitive therapy. Note: OOP: out-of-pocket payment; NHI: national health insurance.

local leaders for a better sample representation. However, our study is not bereft of limitations. Although efforts were made to ensure wide representation across each country, we still obtained a greater number of responses from big cities. Another limitation is that some hospitals may have inadvertently provided more than one response, as we did not capture the hospitals' names due to confidentiality reasons. This might result in a partially complete picture of the state of post-stroke services in some countries. Nonetheless, in large countries like Mexico, the high share and respondents' locations reflect the geographic area. Lastly, most of the responses about individual hospitals were from teaching hospitals, limiting the representation of non-teaching hospitals in the region. However, this information remains relevant, highlighting the need for better services even in the most advanced centres.

In conclusion, access to post-stroke rehabilitation services in Latin American countries is mainly restricted due to a lack of coverage by the public health system, human resources and financial aid. Our study highlighted the public-private divide, with respondents mentioning that post-stroke rehabilitation services are more readily available in private settings. Nonetheless, even patients with private health insurance face barriers to access post-stroke rehabilitation. Future directions include developing consensus guidelines, enhancing guidelines awareness, increasing coverage, and exploring innovative approaches to deliver post-stroke rehabilitation. By investing in the improvement of rehabilitation services and in ways to expand access through cost-efficient interventions governments could reduce the indirect costs by allowing more people to recover from stroke, regain independence, get back to work, and improve their welfare. The progress made since the Declaration of Gramado in 2018 has been significant and must continue to enhance post-stroke services in Latin America.

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## CRediT authorship contribution statement

Alejandro Gonzalez-Aquines: Writing - review & editing, Writing original draft, Methodology, Formal analysis, Conceptualization. Julieta Rosales: Writing – review & editing, Validation, Conceptualization. Ana Claudia De Souza: Writing - review & editing, Validation, Conceptualization. Angel Corredor-Quintero: Writing - review & editing, Validation, Conceptualization. Miguel A. Barboza: Writing review & editing, Validation, Conceptualization. Victor Navia-Gonzalez: Writing - review & editing, Validation, Conceptualization. Florencia Brunet-Perez: Validation, Conceptualization. Javier Lagos-Servellon: Validation. Conceptualization. Nelson Novarro-Escudero: Validation, Conceptualization. Diego A. Ortega-Moreno: Writing review & editing, Validation, Conceptualization. Victor Villarroel-Saavedra: Validation, Conceptualization. Carlos Abanto: Writing review & editing, Validation, Conceptualization. Jose Domingo Barrientos-Guerra: Validation, Conceptualization. Filadelfo Saltos-Mata: Validation, Conceptualization. Vasileios Papavasileiou: Validation, Supervision, Conceptualization. Oliver Todd: Writing - review & editing, Validation, Supervision, Conceptualization. Fernando Gongora-Rivera: Writing - review & editing, Supervision, Methodology, Conceptualization.

## **Declaration of competing interest**

We declare no competing interests.

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## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.jstrokecerebrovasdis.2024.107917.

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