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ARTICLE



From healthcare system to individuals through stroke rehabilitation pathways. Outcomes, information, and satisfaction along 12 months prospective cohort in Portugal

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ABSTRACT

Background: The nature and quality of stroke survivor rehabilitation varies throughout Europe, including in Portugal, having not been widely monitored or benchmarked.

Objectives: This study analyses the stroke care pathway from three perspectives: healthcare system, process, and patient.

Methods: The study uses data from a one-year single-center prospective cohort of first stroke patients, assessed at baseline, 3, 6, and 12 months. Care pathways and settings were described in terms of organizational model, funding, patient involvement, frequency and intensity and multi-disciplinary team. Patient-level information and satisfaction were evaluated using a 10-point numeric rating scale. Kruskal – Wallis and post-hoc tests were used to compare EQ-5D-3 L, National Institute of Health Stroke Scale (NIHSS), Modified Rankin Scale (mRS), Barthel Index, Mini-Mental State Examination scores between pathways and settings.

Results: A total of 391 acute stroke patients, with a mean disability of 3.7 (mRS) and severity of 11.7 (NIHSS) participated. Six pathways and eight settings were described. A lack of compliance between guidelines and care was identified. There were significant differences in the four outcomes between the six pathways (p-values 0.007 to 0.020) suggesting inefficiency and inequalities, with an inadequate level of information and patient satisfaction. After post-hoc analysis, pathways 1 and 2 showed highest outcomes (p-values 0.001 to 0.002). Within settings, short-term units showed high scores, followed by rehabilitation center, outpatient hospital, and community clinic (p-values 0.001 to 0.040).

Conclusion: A multilevel characterization of the post-stroke rehabilitation pathway showed a more complete perspective on stroke management which may contribute to future rehabilitation and stroke policies

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Introduction

Despite considerable advances across the care pathway (prevention, treatment, and rehabilitation), stroke is a leading cause of adult disability in Europe,^{1,2} with major health, economic and societal implications.³ Although rehabilitation can be a cost-effective service,⁴ it has not been prioritized in many countries, is under-resourced,⁵ and has been largely neglected by the research field.⁶

There are no universally agreed guidelines and outcomes for rehabilitation in post-stroke patients

across European countries,^{7–9} where different health service structures and payment systems often determine inconsistent pathways of care.¹⁰ Stroke survivors across Europe face long waiting lists to start rehabilitation. Often, rehabilitation takes place over a short period, without being sufficiently intensive, and often fails to address depression and cognitive impairment.^{6,11,12} Many patients express dissatisfaction and refer to a high burden of unmet needs,¹³ with very few receiving follow-up reviews and long-term support.¹²

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Recent reports have shown that rehabilitation policies aimed at increasing quality of care across Europe are not widely monitored or benchmarked.^{6,11} A few countries have well established audit programs,¹¹ although most completely lack or have fragmented healthcare data collection for quality improvement.¹² Stroke treatment services in Portugal rank among the less developed in Europe,¹⁴ with scarce and outdated information about the rehabilitation setting.¹¹ This study analyses the Portuguese stroke post-acute care system and contributes to the understanding between different stroke health and rehabilitation care systems in Europe.

New settings of care should be designed to meet the targets set for 2030 by the *Action Plan for Stroke*.¹⁰ It is also imperative to overcome the gap between the rhetoric around unsustainable healthcare systems and the investment in the transformative change that is required for the widespread uptake of integrated care models and an effective navigation through complex health systems.^{10,15} To achieve this, data about stroke rehabilitation settings and pathways of care, need to be forthcoming.¹⁶

The general approach we adopted in this study was a three-level analysis of the stroke care pathway, at the system, process, and patient level. The primary aims were to (i) describe alternative coexisting stroke pathways in Portugal, (ii) describe each rehabilitation pathway regarding the care settings, characteristics. Secondary aims were to (iii) determine the level of information available and patient satisfaction throughout the duration of the stroke care pathway.

Methods

Study design

This study used data from a one-year single-center prospective cohort study of 391 acute first stroke patients and their primary caregivers. Patients were interviewed up to four times, once in the first seven days after stroke, and three follow-up home visits at 3, 6 and 12 months after discharge. Data was collected from September 2018 to November 2020, with the last enrollment in November 2019.

After admission to a large public hospital in the North of Portugal all stroke cases were flagged

through an automatic digital search query ($n = 523$) and then screened for eligibility using clinical records. Participants and primary caregivers were informed and invited to participate in the study by a healthcare professional from the hospital, independent of the research team, who explained the study to the potential participants and obtained informed consent. The study was reviewed and approved by the Ethics Committee of the Local Health Unit of Matosinhos (No. 57/14/RS).

The study sample was restricted to patients able to respond to patient-reported outcome measures independently. Patient-level data was obtained from in-person interviews combined with data from clinical records, while system and process-level data were extracted from patient interviews combined with data from institutional records. The interviewer followed a data collection guideline to standardize the procedure.

To improve continued participation, subjects were contacted by phone one week before each interview and reminded one day before the visit. If a participant did not answer phone calls on three different days or deceased, they were considered lost to follow-up. The sample diagram can be consulted in the supplementary material (Appendix S1). There was no missing data in the study variables.

Further details of the study design and of the sample are reported elsewhere.¹⁷ This manuscript conforms to the STROBE Guidelines.

Pathways, settings of care, patients characteristics and outcomes

Portugal has a healthcare system based on a National Health System (NHS), with eight rehabilitation care settings described as follows: Short-term Unit (Short-term), Medium-term Unit (Medium-term), Long-Term Unit (Long-term), Rehabilitation Centre (Rehab-center), Home-based Rehabilitation (Home-based), Day Hospital (Day-hospital), Community Clinic (Community-clinic), Private Clinic (Private-clinic).

The pathway variable was defined using the sequences of different settings of rehabilitation care over the first-year post-stroke. In each follow-up assessment, patients were asked about the setting where the rehabilitation plan had taken place

since the last assessment, building up a multistep care sequence during rehabilitation.

The research data was organized into system, process, and patient levels.

At the healthcare system level, the rehabilitation care pathway was described and for each rehabilitation setting, six variables were collected: 1) the sector of care, 2) the model of care, 3) the nature of provider, 4) funding source and 5) patient co-payment, 6) time frame from admission to discharge.

At the process level, each rehabilitation setting was described using six variables: 1) admission assessment, 2) discharge plan, 3) patient involvement in the definition of rehabilitation goals, 4) multidisciplinary team available, 5) frequency and 6) duration of clinical sessions.¹¹

At the patient level, the data collected was organized into five groups: 1) pre-stroke sociodemographic characteristics, 2) healthcare characteristics, 3) outcomes, 4) information level and 5) satisfaction level. Pre-stroke disability level was not available in the clinical records and was not assessed retrospectively to prevent recall bias. Cardiovascular risk factors followed the standardized values for the population.

Outcomes were assessed using the following instruments: stroke severity – National Institute of Health Stroke Scale (NIHSS Scale),¹⁸ functional status – Barthel Index (BI),¹⁹ neurological disability – Modified Rankin Scale (mRS),²⁰ neurocognitive function – Mini Mental State Examination (MMSE),²¹ and HRQoL – EQ-5D-3 L.²²

The information and satisfaction levels were measured by a 10-point numeric rating scale (NRS).^{23–25} Zero represents the lowest perceived level and 10 represents the highest.

At hospital discharge, each patient assessed their level of information over eight dimensions: 1) primary diagnosis, 2) functional prognostic/expected outcomes, 3) daily care training, 4) medication plan, 5) professional of contact, 6) costs of subsequent rehabilitation care, 7) next rehabilitation services and facilities and 8) geographical location of next rehabilitation setting.

At each rehabilitation setting, every patient assessed their level of satisfaction over six dimensions: 1) referral process, 2) available information, 3) rehabilitation outcomes, 4)

intensity of rehabilitation care, 5) family involvement, and 6) patient involvement.

Statistical analysis

Categorical variables were described using frequencies and percentages and continuous variables were described with means and standard deviations or medians and interquartile ranges for variables without normal distributions. The satisfaction level for each setting resulted from the average of the scores of the six dimensions.

Outcomes were assessed by setting of care and by pathway. For the setting assessment, the moment of entry was defined as the moment of evaluation. For the pathway assessment, moment of entry was defined as the 12-month follow-up.

The Kruskal – Wallis test was used to compare continuous variables (i.e. mRS, EQ-5D-3 L, BI and MMSE) between groups (i.e. the different settings and pathways). Whenever a statistically significant result was determined, a post-hoc test (Bonferroni) was used to explore the existence of statistically significant differences among the different groups being compared.

The significance level was fixed at 0.05. Whenever multiple comparisons were applied, a Bonferroni correction of the alpha level was used to correct for the family-wise error; in these circumstances, a significance value of 0.002 was assumed. All the analyses were conducted using SPSS v.28.

Results

Sample description

The final cohort consisted of 391 patients, and 349 (89%) were followed up to 12 months (Appendix S1). Participants had a mean age of 74.4 years (SD = 12.9), and 52.7% were women. Approximately 85% of stroke patients were older than 60 years of age.

Stroke disability upon first assessment was ≥ 3 in 81.5%, and functional status showed a mean/sd of 60.1/29.5 (Barthel Index). The sample functional state was 60.2 and the neurocognitive function mean was 24.2. Regarding healthcare variables, the mean acute hospital inpatient stay was 43 days (SD = 16 days), and the proportion of consecutive weeks

Table 1. Sample description.

Pre-Stroke Characteristics (n=391)		Baseline Clinical and Health Care Characteristics (n=391)	
Age (years), mean (sd)	74.4 (12.9)	Subtype of stroke OXFORD, n (%)	
20-40	4 (0.9)	PACS	144 (36.4)
41-60	56 (14.2)	LACS	90 (23.6)
61-80	177 (45.3)	POCS	73 (18.5)
81-100	155 (39.6)	TACS	32 (8.3)
Sex, n (%)		Hemorrhagic	51 (13.2)
Male	185 (47.3)	mRS Scale, mode	3
Female	206 (52.7)	mRS Scale, n (%)	
Marital status, n (%)		No symptoms at all (0)	0 (0)
Married/Civil Union	206 (52.7)	No significant disability (1)	7 (1.7)
Divorced	138 (35.4)	Slight disability (2)	66 (16.8)
Widowed	28 (7.1)	Moderate disability (3)	156 (39.9)
Single	19 (4.8)	Moderately severe disability (4)	98 (25.1)
Education, n (%)		Severe disability (5)	65 (16.5)
Elementary School	192 (49.0)	Mini Mental State Examination, mean (sd)	24.2 (3.1)
Middle School	125 (31.9)	Barthel Index, mean (sd)	60.2 (29.5)
High School	75 (19.1)	Slight dependency (91-99)	30 (7.7)
Current Residence, n (%)		Moderate Dependency (61-90)	179 (45.8)
Home	323 (82.6)	Severe Dependency (21-60)	143 (36.5)
Institutionalized	68 (17.4)	Total Dependency (0-20)	39 (9.9)
Occupation, n (%)		EQ-5D-3 L, mean (sd)	0.15 (0.41)
Retired	271 (69.2)	Length of acute hospital stay (days), mean (sd)	41 (16.7)
Employed	109 (27.9)	≤15 days, n (%)	108 (27.6)
Unemployed	11 (2.8)	≥15 days, n (%)	283 (72.4)
Patient monthly income (€), n (%)		Consecutive rehabilitation (weeks), mean (sd)	
≤1000	252 (64.5)	At 3 months follow-up	10.2 (0.8)
>1000	139 (35.5)	At 12 months follow-up	19.9 (6.4)

sd – standard deviation; % - frequency; mRS – Modified Rankin Scale; EQ-5D-3 L – EuroQol 5D.

PACS – Partial Anterior Classification Stroke; TACS – Total Anterior Circulation Stroke; POCS – Posterior Circulation Stroke; LACS – Lacunar Stroke.

of rehabilitation care decreased from 85.3% (10.2/12) at 3 months to 41.5% (19.9/48) at 12 months (Table 1).

Stroke care pathways

Eleven pathways are graphically displayed in Figure 1, however, due to sample size limitations, the analysis was performed between the six most prevalent pathways (Appendix S2).

After hospital discharge, most patients were referred to Medium-term (41.3%), followed by Short-term, Rehab-center, and Day-hospital with percentages between 17.4 and 19.9%. Finally, 13.4% of patients were referred to Long-term.

At the 3-month follow-up, the use of the Medium-term setting became even more dominant ensuring care for 62.1% of patients. Between the 6- and 12-month follow-up, there was a change in the use of available settings. Community clinics led caring for between 63.8 and 76.8% of patients. At six months, 21.4% of patients received Home-based care, and some began using Private-clinic and continued to do so for at least 12 months (8.6%-14.5%) (Figure 1).

Settings of rehabilitation care

The characteristics of the different settings are outlined in Table 2 and described further in Appendix S3.

Healthcare systems-level data showed that six rehabilitation settings are managed within the health sector, and two integrate health and social sectors. In six settings, the NHS is the funder and provider, while in one setting the NHS finances but care is provided by a private partner. In the Private-clinic, the financier and provider are both private. Among the seven options financed by the NHS, in five, the patient is not charged, and in two, payment varies according to the patient's income. In the private sector, payment is fully out-of-pocket.

Process-level data demonstrated that the time-frame of each setting varied between a maximum of 30 days and unlimited time. In all settings, the patient received a clinical assessment upon admission. Only three settings involved the patient in the definition of rehabilitation plan goals, and in three they did not receive a discharge plan.

Access to multidisciplinary care was heterogeneous between settings. All settings provided medical and physiotherapy care, 75% of the settings provided speech therapy, 50% included

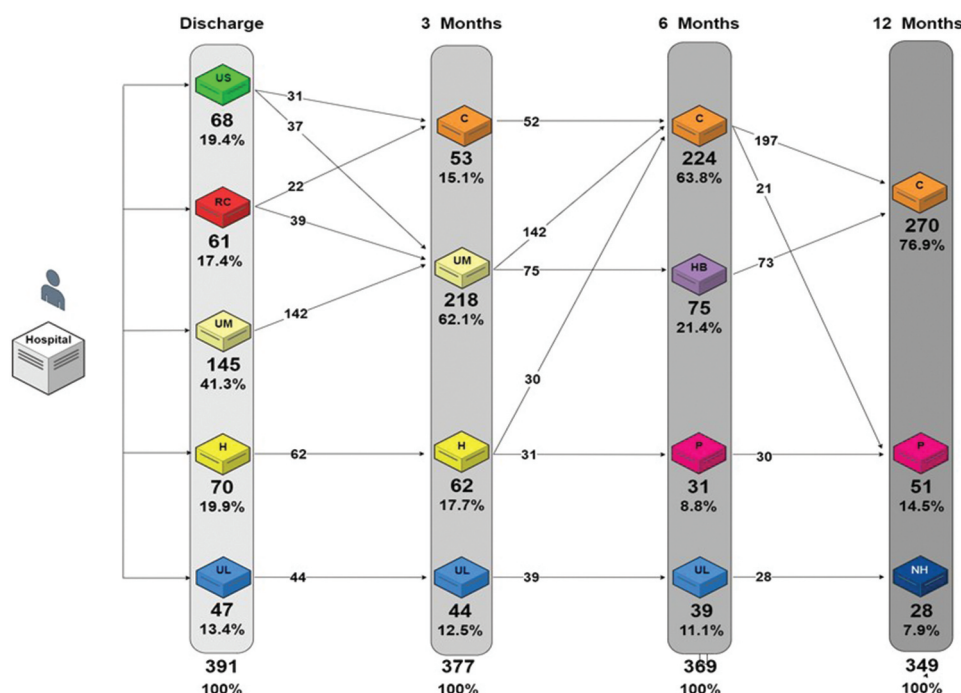


Figure 1. Eleven rehabilitation pathways in the first year after stroke in Portuguese NHS. Note: US - Short-term Unit; UM - Medium-term Unit; UL - Long-Term Unit; RC - Rehabilitation Center; HB - Home-based; H - Hospital; C - Community Clinic; P - Private Rehabilitation.

rehabilitation nursing, 38% involved occupational therapy, and only 25% offered psychology/cognitive rehabilitation. The frequency of physiotherapy sessions ranged from 3 to 12 sessions per week and the duration of rehabilitation sessions ranged from 30 to 60 minutes each.

Outcomes

At the patient-level data, the four outcomes – mRS, EQ-5D-3 L, BI and MMSE were evaluated by pathway and by setting.

At 12-month follow-up, pathways 1 and 2 showed the highest scores at the four outcomes followed by pathway 5 (Figure 2 and Appendix S4). The Kruskal-Wallis test showed significant differences in the four outcomes between the six pathways (p-values between 0.007 and 0.020). After post-hoc analyses, all comparisons showed significant differences (p-values between 0.001 and 0.002), except for pathway 1 and 2 at all outcomes, for pathway 3 and 4 at EQ-5D-3 L, BI and MMSE, for pathway 1 and 5 at MMSE, and pathway 2 e 5 at EQ-5D-3 L, mRS and MMSE.

At entry level, Short-term units showed higher values, followed by Rehab-center, Day-hospital,

Private-clinic, and Community-clinic with moderate values, and Home-base, Medium-term and Long-term with lower values (Figure 3). Significant differences were found in all four outcomes between the eight settings after conducting post-hoc analyses (p-value between 0.0001 and 0.002) (Figure 2 and Appendix S5).

Patient information and satisfaction

At hospital discharge, patients self-reported being fully informed (9/10) about the geographic location of the next rehabilitation setting, moderately informed (5-7/10) about the medication plan, primary diagnosis, and costs, poorly informed (2-3/10) about functional prognosis, expected outcomes, expected services and contact professional (Figure 4). The results by item can be found in Appendix S6.

Between setting, patients reported high satisfaction at the Rehab-Center (9/10), Short-term (8/10), and Day-hospital (7/10) with an emphasis on intensity of care, outcomes obtained and patient involvement dimensions. They reported moderate satisfaction with rehabilitation care in Private-clinic (6/10) and Medium-term (5/10), and they reported low

Table 2. Settings of care description.

CLINICAL SETTING	US	UM	UL	RC	HB	H	C	P
CARE SERVICES	Short-term Rehabilitation Unit	Medium-term Rehabilitation Unit	Long-term Rehabilitation Unit	Rehabilitation Center	Home-based Rehabilitation	Day Hospital	Community Rehabilitation Clinic	Private Rehabilitation
MODEL OF CARE	Health Inpatient	Health/Social Inpatient	Health/Social Inpatient	Health Inpatient	Health Home-based	Health Outpatient	Health Outpatient	Health Home-based/ Outpatient
PROVIDER	Public (NHS) Yes	Public (NHS) Yes	Public (NHS) Yes	Public (NHS) Yes	Public (NHS) Yes	Public (NHS) Yes	Private Yes	Private No
STATE FUNDING	Free	Progressive according to income	Progressive according to income	Free	Free	Free	Free	Total
PATIENT FUNDING								
ADMISSION TO DISCHARGE TIME (days)	30	30 - 90	≥90	50-60	60-120	30-150	Unlimited	Unlimited
ADMISSION ASSESSMENT	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
DISCHARGE PLAN	Yes	Yes	Yes	Yes	Yes	No	No	No
AGREE REHAB GOALS	Yes	Yes	No	Yes	No	No	No	No
MULTIDISCIPLINARY TEAM	P/PT/ST	P/PT/ST	P/PT	P/PT/RN/PSI/ST/OT	P/PT/RN	P/PT/ST/RN	P/PT/ST/OT	P/PT/ST/OT/PSI
FREQUENCY OF PHYSIO SESSIONS (week)	8-12 s	5	3	10 - 12s	3 - 4s	5	3 - 5s	3 - 5s
PHYSIO SESSION DURATION (min)	60	45	30	60	30	45	45	60

US – Short-term Unit; UM – Medium-term Unit; UL – Long-term Unit; RC – Rehabilitation Center; HB – Home-based; H – Hospital; C – Community Clinic; P – Private Rehabilitation.

NHS – National Health System.

P – Physician; PT – Physiotherapist; ST – Speech Therapist; OT – Occupational Therapist; RN – Rehabilitation Nurse; PSI – Psychologist.

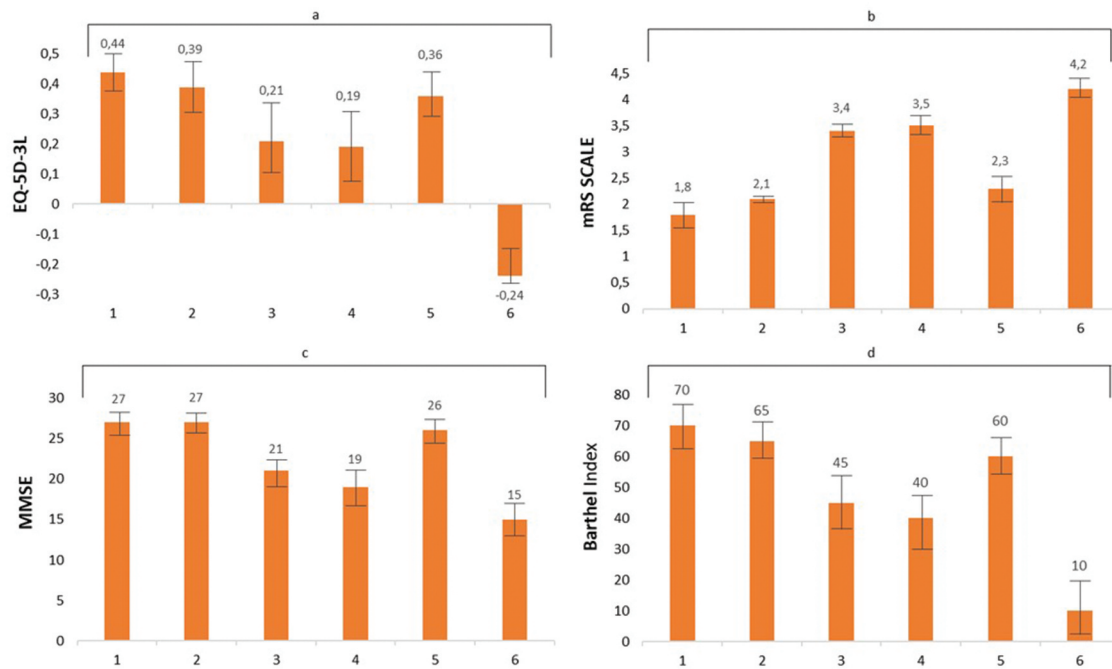


Figure 2. Final outcomes by pathway. Overall p-value: a=0,002; b=0,007; c=0,02; d=0,004. All post-hoc comparisons showed significant differences (p-value between 0.0003 and 0.002), except for pathway 1 vs 2 at all outcomes, for pathway 3 vs 4 at EQ-5D-3L, BI and MMSE, for pathway 1 vs 5 at MMSE, and pathway 2 vs 5 at EQ-5D-3L, mRS and MMSE.

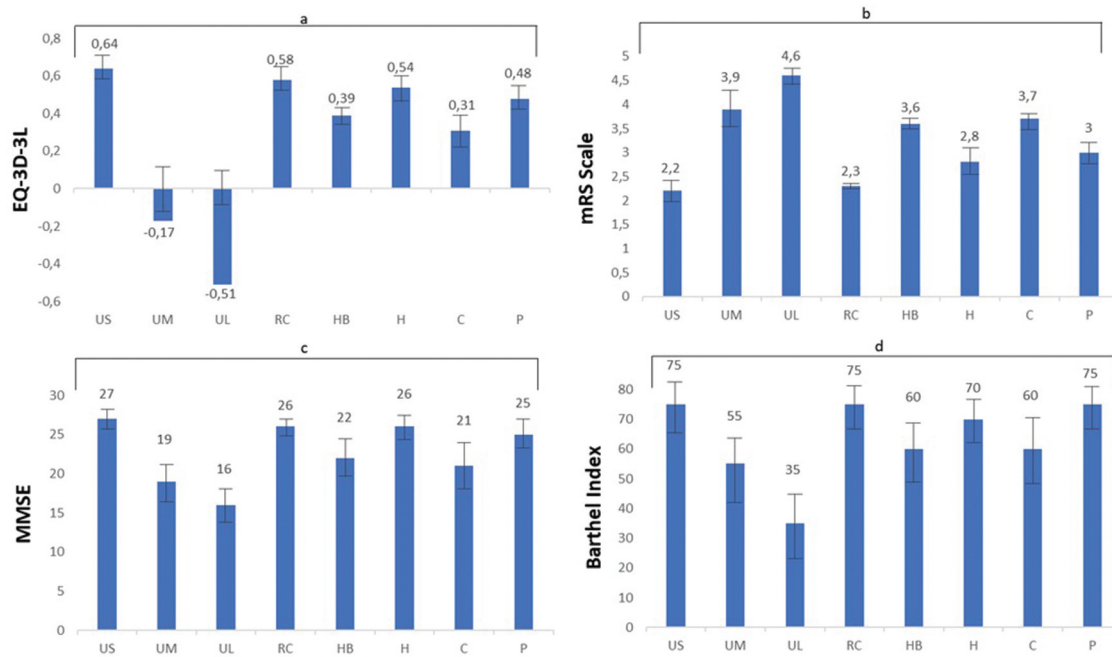


Figure 3. Baseline outcomes by setting of care. Note: US - Short-term Unit; UM - Medium-term Unit; UL - Long-Term Unit; RC - Rehabilitation Centre; HB - Home-based; H - Hospital; C - Community Clinic; P - Private Rehabilitation.

satisfaction levels with the Home-base, Community-clinic (3/10) and Long-term (2/10) settings

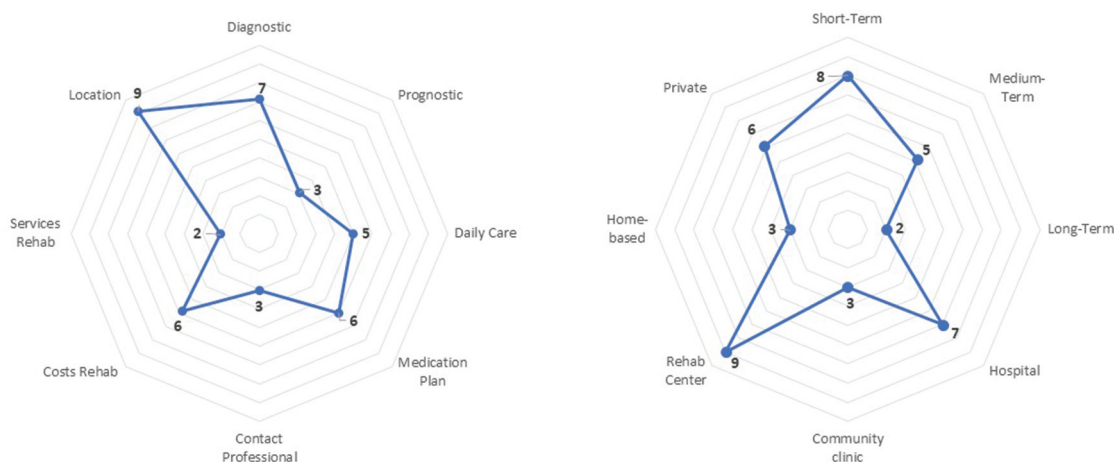


Figure 4. Information level [0-10] at hospital discharge and satisfaction level [0-10] by clinical setting.

(Figure 4). The results by item can be found in Appendix S7.

Discussion

The results highlighted six main rehabilitation pathways in a combination of eight different health care settings in Portugal.

The existence of multiple care options and alternatives can be seen as positive from a person-centered care perspective, where healthcare solutions are adapted to patient needs.^{26,27} However, fragmentation of settings and pathways is not always synonymous with more developed health systems. Our results showed pathways with similar outcomes after 12 months of care, suggesting inefficiency. Simultaneously, important outcome differences were found between other pathways of the same healthcare system, which raises questions about the equity of care.

The process of fragmentation of care through differentiation can have implications for all stakeholders.²⁸ The element of payment loses efficiency and coordination, and the provider becomes solely responsible for its intervention linked to its own culture and organization.²⁹ The patient can be disoriented throughout the healthcare system, may have low levels of information regarding the available therapeutic options, as well as the specificity of each level of intervention.^{30,31} This explains losses in access and quality, a scenario that leads to lower gains and increased costs.³¹

Given the complex health care delivery network, this study, based on system and process data sought to understand whether the existing solutions of care followed best practice guidelines^{32–35}. This is consistent with European reports that describe flaws in the type and quality of stroke care,^{11,12} which are common challenges for European health systems.

Portuguese guidelines on patient referral determine that mild stroke patients should be referred to a Day-hospital or Rehab-center³⁶. In the study sample, one third of patients were referred to Short-term units not considered at national guideline. Furthermore, severe stroke patients under 55 years have indication for specialized hospital admission,³⁶ while the results showed that the norm was never respected. Referral appears to be more accurate in the mild and severe stroke cases. While the intermediate categories of age and severity, as they include higher samples, with a greater range of clinical manifestations and individual characteristics, tend to present less compliance with the norms.

On other hand, as early hospital discharge is recommended,^{32–35} our study sample's mean hospital stay was 43 days (SD = 16 days), which warns that the transfer to the subacute phase is not fast and continuous. Furthermore, merely the Short-term and Rehab-center settings guarantee the suggested interdisciplinary and intense care, however restricted to 30–60 days, which means that only 30% of the study sample was able to obtain such care. This demonstrates the need to invest in more intensive settings.

Finally, the guidelines point to the relevance of transition planning between settings,³² but only 60% offer transition planning and only 35% involve the patient in goal setting.

This lack of agreement between the good practice defined by guidelines and the care provided occurs in different European countries^{37–39} and may suggest two phenomena. The first possibility is that there is a lack of knowledge and systemic integration of the guidelines into the decision-making process by professionals and health systems.⁴⁰ The second is that the guidelines are not adapted to the complexity of the process⁴¹. These findings show that professional and policy strategies are required to overcome barriers to evidence-based stroke rehabilitation.^{41,42}

At patient-level, the results demonstrate that the pathway after stroke is not followed by an adequate level of information aligned with the literature.^{16,43} This leads to unstable and disorganized navigation accompanied by a reduced perception of control, a combination of factors that justify distrust in the healthcare system.¹³ Concurrently, our data shows that patient satisfaction is consistent with best practice intention,²⁸ with higher values in settings with more intensive and multidisciplinary care and greater involvement of the patient/caregiver. The gaps in the level of information and patient satisfaction are similar to the European trend in this field.^{11,12,44}

The projections from the Burden of Stroke in Europe indicate that in 2047 the total number of stroke survivors in the European Union will increase by 27%.¹¹ Thus, it is paramount that the Helsingborg Declaration that defended that “all stroke patients in Europe have access to the continuum of rehabilitation care from the acute stage” be revisited.¹⁰

As emergency stroke care was optimized in the past, new simpler rehabilitation pathways must be created that are less fragmented, more homogeneous and closer to the guidelines.

The possibility of cooperating in providing information on the rehabilitation stroke pathways from healthcare system to patient perspective with a wide range of age, stroke subtypes, degrees of severity and rehabilitation data collected over the year, is one of the main strengths of this paper. In fact, to the best of our

knowledge, this is the first article that systematically accesses and describes the real pathways of stroke in Portugal.

This study also has some potential limitations. The generalizability of our results is limited by the fact that the study is based on a single-center cohort of 391 stroke survivors from the Portuguese health system. In addition, the exclusion of the data from patients with communication impairments or deceased may have created a selection bias. For that, a higher initial sample was required at recruitment to accommodate a loss of greater than 23% of patients, as can be consulted in Appendix S1. Proxy responses were excluded, as proxies tend to overrate the severity of a patient's condition.⁴⁵ With a prospective follow-up study design, it was inevitable that some individuals were lost to follow-up, a potential form of selection bias. In addition, it was not possible to assess some pathways due to the impact of stratification by the various rehabilitation options, and therefore, studies with a larger sample size and of a multicentric design are needed. Future studies should consider some patient characteristics like associated comorbidities, ICU stay, and ventilatory requirement.

Conclusion

This study provides a useful contribution to the literature by characterizing the post-stroke rehabilitation pathway, allowing us to understand the existence of a heterogeneous healthcare system, with losses in effectiveness and efficiency. These findings can contribute toward the innovation and transformation of rehabilitation care for stroke survivors, leading to improvement of care and stronger bonds of trust between patients and the health system.

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The authors report that they have no competing interests to declare.

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