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Long-Term Outcome in Stroke: The Need of Individualized Follow-Up

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ABSTRACT

Introduction: It is well established that in the long-term, many stroke patients potentially have relevant functional incapacity related to deficits in domains other than motor; the burden of unmet long-term needs likely varies between different types of stroke or different healthcare systems. On the other hand, we can say that the ideal length of follow-up in a specialized consultation after ischemic stroke has not been established.

Methods: We evaluated long-term stroke patients who underwent endovascular treatment of anterior circulation in our stroke center and that were classified as "therapeutic success" (modified Rankin scale - mRS < 3) at 3 months, to participate in an observational, cross-sectional study. Participants underwent a comprehensive interview and examination using validated standard questionnaires for Portuguese population to assess different life aspects after stroke as Post-Stroke Checklist, EQ-5D-3L scale, mRS, Barthel Index (BI), Burden Scale for Family Caregivers and Hamilton scale.

Results: We evaluated 36 patients. The mean age was 67.6 years old $(\pm 13,8)$ and the mean time for the interview was 52,8 $(\pm 9,9)$ months after the stroke. Most patients were independent, with a mean mRS of 1 (ranging from 0–3) and BI 95,4 (70-100). Sixty one percent had a clinically significant deficit in at least one domain. On the Post Stroke Checklist (PSC), 77,8% of participants demonstrated a not good perceived health status. EuroQoL index value was 0.750 (IQR 0.664–1.00). The two major disability parameters identified were in cognition (52,8%) and depression (27,8%). After review of the ongoing care by stroke specialists, in almost 2/3 of the patients, additional measures were proposed: additional etiological investigation (44%), physical or speech rehabilitation (~14%) or changes in pharmacological therapy (~3%).

Conclusion: These results highlight the prevalence and importance of non-motor disabilities in long-term stroke patients, even after short-term classification as "therapeutic success". We also point out that even after more than 3 years of the stroke, additional therapeutic or etiological investigation measures were taken, reinforcing the need for individualized follow-up, without a pre-defined maximum follow-up time in a specialized cerebrovascular pathology consultation.

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Keywords

Stroke, Disability, Unmet needs, Quality of life.

Introduction

Ischemic stroke is a major cause of long-term disability [1]. Despite the increasing quality and well-known benefits of the acute reperfusion treatments on functional prognosis at 3 months [2-7], only a few studies have investigated long-term outcomes and most of these focus on single parameters, such as motor disability or cognitive impairments [8-13].

Functioning is a health indicator and relates to a person's ability to perform tasks, to be involved in life situations and to fulfil expected social roles, considering physical, psychological and environmental factors [14-16]. The International Classification of Functioning, Disability and Health, developed by the World Health Organization, assess these dimensions and indicates that each of them has the potential to influence patients' perceived satisfaction and, therefore, quality of life [14-16]. Additionally, unmet health, rehabilitation and social needs in stroke survivors are associated with incapacity and lower quality of life [17-20]. One of the main objectives in stroke acute reperfusion treatments is to reduce the incapacitation on the patients' functioning after the event [14-16]. Taking this into account, it seems somewhat simplistic and incorrect to define stroke long-term prognosis considering only scales that assess motor skills.

Stroke care demands appear to change over the years, so it is plausible that a long-term follow-up should be beneficial [8,18]. Interdisciplinary collaboration between different medical specialties (neurologist, physiatrician, etc), psychologists and social services, in association with patient and caregiver perspective, is essential to define interventions that might reduce stroke-related morbidity [17,18]. This assessment can also be a key foundation for the development of new and more comprehensive scales, to be used in the follow-up of these patients [21]. The Managing Aftercare for Stroke (MAS-I) study was recently published, emphasizing the importance of a comprehensive assessment of long-term stroke patients and revealing significant unmet needs in health and social care in their sample [22].

The aim of this study is to evaluate the unmet needs, disease burden and current treatments in stroke patients submitted to mechanical thrombectomy who were considered as having a good outcome at 3 months. We also aimed to to understand whether even after a long period of time post-stroke, and after evaluation by a multidisciplinary team specialized in cerebrovascular pathology, therapeutic changes and/or additional investigation would be proposed in a significant percentage of patients.

Methods

We conducted a cross-sectional observational study of post rehabilitation patient needs and caregiver burden after stroke in a sample of patients in our stroke centre. We have followed a similar assessment protocol to that carried out by MAS-I but in our case, target population consisted of the first patients treated with mechanical thrombectomy for acute ischemic stroke of anterior circulation in our stroke centre and that were autonomous in activities of daily living at 3 months (modified Rankin scale - mRS <3), since this population is considered, according to stroke treatment clinical trials, as a "therapeutic success" [6,23,24].

Sampling and Recruitment

The study included all consecutive adult patients with anterior circulation large vessel occlusion who were treated with mechanical thrombectomy starting in February 2015, with mRS <3 at 3 months and more than three years between the stroke and our evaluation. The aim was to select a relatively homogeneous population regarding stroke severity, treatment performed as well as good short-term motor prognosis. Other eligibility criteria were the residency in our hospital area and 18 years of age or older. Written informed consent was obtained from all participants.

Assessment

Thirty-six patients were examined by a multidisciplinary team consisting of a neurologist, a physiatrist and a speech therapist. We assembled assessments considered standards in the following domains: self-reported needs (Post-Stroke Checklist), quality of life (EQ-5D scale), overall outcome (modified Rankin scale, Barthel scale), dysphagia (Eat Assessment Tool, Functional Oral Intake scale), cognition (Montreal Cognitive Assessment), aphasia (adapted Lisbon Aphasia Assessment Battery), depression (Hamilton scale), secondary prevention (Morisky Adherence Questionnaire) and caregiver burden (Burden Scale for Family Caregivers). All used scales are validated for Portuguese. Cut-off points are listed in table 1. Patients were evaluated by a physiatrist trained to evaluate spasticity.

The examination consisted of 2 parts: firstly, patients' health related situation was assessed in a standardized interview. Subsequently, scales were applied to evaluate the above-mentioned domains. One examination lasted 2 to 2.5 hours. When present, the caregiver was asked to complete the Burden Scale for Family Caregivers (BSFC). In autonomous patients who attended alone, this scale was not applied (Table 1).

Table 1: Domains assessed and cut-off measures.

Domains	Assessment	Cut-offs used	Reference
Self-reported need	Post-Stroke Checklist (PSC)	>0 points	[25]
Quality of life	EuroQoL (EQ-5D)		[26]
Overall function	Modified Rankin Scale (mRS) Barthel-Index (BI)		[27,28]
Dysphagia	Eat Assessment Tool (EAT-10) Functional Oral Intake scale (FOIS)	>2	[29,30]
Aphasia	Lisbon Aphasia Examination Battery (adapted)	Fluent or non-fluent speech Nomination <16 Comprehension <7 Repetition <23	[31]

Cognitive deficits	Montreal Cognitive Assessment	<22 points for mild cognitive impairment <17 points for dementia	[32,33]
Depression	Hamilton Depression Scale (HAM-21)	>9 points	[34]
Secondary prevention	Morisky Adherence questionnaire	>2 points	[35]
Caregiver burden	Burden Scale for Family Caregivers	>35 points	[36]

Comparing current treatment plans to guidelines

To identify factors that may pose a need for access to health care or adjust secondary prevention measures to meet international guidelines, all evaluated patients were screened. The recommendations were grouped into the following groups: none, medical review (need for further diagnostic workup or need for new medical care), change in medication or need for further rehabilitation. The treatment plan was subsequently communicated to patients.

Results

Study population

A total of 141 patients met the inclusion criteria of the study data; 33 patients were deceased by the time of enquiry; 78 patients could be located and 25 patients refused to participate (Figure 1).

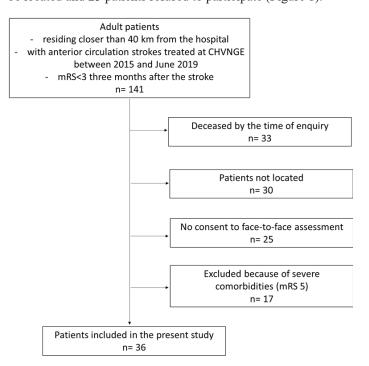


Figure 1: Flow chart of patient inclusion and exclusion data.

CHVNGE indicates Centro Hospitalar de Vila Nova de Gaia e Espinho and mRS modified Rankin scale.

Demographic and baseline stroke characteristics, comorbidities, secondary prevention, previous treatments and ongoing care of the study population is shown in table 2. Patients were evaluated

a mean of 53 months (ranging 33-83) after stroke onset. At time of assessment the mean mRS was 1 (ranging from 0–3) and 33 (91,7%) patients were categorized as "independent" (mRS <3). The mean BI was 95,4 (ranging from 70-100). Two patients had new cerebrovascular events and the secondary prevention therapy, namely antiplatelet medications and anticoagulation, was changed in both. Thirty-fivepatients interviewed were medicated with antiplatelet agents (44,4%) or anticoagulation (52,8%) as a form of secondary stroke prevention. Sixty ninepercent of patients had ongoing general practitioner support and 25% were regularly seen by a neurologist. The remaining 6% of patients currently do not have any regular medical follow-up.

Reported health

Based on the clinical scales, 61,1% (22 patients) had a clinically significant deficit in at least one domain. Table 3 shows patient needs at evaluation, according to the validated clinical scales. EuroQoL index value and visual analogue scale were 0.75 (mean, IQR 0.664-1.00) and 72,6 (mean, IQR 60-82,5), respectively. On the Post Stroke Checklist (PSC), 77,8% of participants demonstrated a not good perceived health status and reported at least one clinically significant stroke-related health problem (Table 4). The categories most frequently marked as impaired were cognition (61,1%) and mood (50%). All patients reported good therapeutic adherence, with no patient scoring more than 2 points on the Morisky Adherence Ouestionnaire.

Nineteen patients (52,8%) showed significant cognitive deficits, with thirteen (36,1%) presenting with score criteria for dementia according to Montreal Cognitive Assessment. Ten patients (27,8%) showed a clinically relevant depressive syndrome. Burden Scale for Family Caregivers was applied in 14 caregivers, with 13,9% (5 caregivers) reporting moderate to high levels of stroke-related caregiver burden. To access the value of the PSC scale as a screening test, the complaints reported in the PSC were compared with the changes found in the clinical scales. Of the 22 patients who marked cognition as an unmet need in PSC scale, 15 (68,2%) had deficits in the corresponding clinical scale (MoCA). Of the 18 patients who reported mood changes in PSC scale, 50% had deficits in the corresponding clinical scale (HAM-21).

Care Compared to Guidelines

After review of the ongoing care by stroke specialists, the following measures were proposed: medical review (44,4%), change in pharmacotherapy for secondary stroke prevention (2,78%) and additional outpatient therapy (13,9%), e.g. physiotherapy or speech therapy. The main factors prompting medical review were: perform additional diagnostic tests, aiming completing the stroke etiological study or to reassess vascular risk factors in patients who lost medical follow-up and start follow-up for mood or cognitive disorders.

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Table 2: Population characteristics, secondary prevention and prior therapies.

n (%)	36 (100)
Age, mean (SD)	67.6 (13,8)
Sex, n female (%)	18 (50)
Admission NIHSS, mean(SD)	13,6 (5,1)
Lateralization, n right hemisphere (%)	15 (40)
mRS at three months, mean (SD)	1 (0,7)
Months since stroke, mean (SD)	52,8 (9,9)
Comorbidities, n (%)	
Diabetes mellitus	6 (16,7)
Atrial fibrilation	11(30,6)
Hypertension	22 (61,1)
Smoking	11 (30,6)
Hyperlipidemia	20 (55,6)
Recurrent cerebral infarction	2 (10)
Aetiology - TOAST class, n (%)	
Large artery disease	10 (27,8)
Cardioembolism	13(36,1)
Undetermined etiology	13 (36,1)
Current secondary prevention, n (%)	
Oral AC	19 (52,8)
Platelet inhibition	16 (44,4)
Antihypertensives	25 (69,4)
Antidiabetics	3 (8,3)
Statins	28 (77,8)
Previous therapies, n (%)	
Speech therapy	12 (33,3)
Occupational therapy or physiotherapy	13(36,1)
Ongoing care, n (%)	
Rehabilitation	4 (11,1)
Follow-up by neurologist	9 (25)
Follow-up by generalist	25 (69,4)

BI: Barthel Index; NIHSS: National Institutes of Health Stroke Scale; mRS: Modified Rankin Scale. AC: anticoagulants. Numbers given are presented as median (standard deviation (SD)) if not specified otherwise.

Table 3: Clinical and patient-reported outcome measures and recommendations by stroke specialists.

Scales	Mean (range)
Current mRS	1 (0-3)
Current BI	95,4 (70-100)
EQoL-5D IV	0.750 (0.664–1.00)
EQoL-5D VAS	72,6 (60-82,5)
Any need in PSC (score>0), n (%)	28 (77,8)
Significant spasticity, n (%)	2(5,56)
Non-compliance (Morisky)	0 (0-1)
Speech impairment (LAEB), n(%)	4 (11,1)
Dysphagia (EAT-10)	0 (0-1)
Dysphagia (FOIS)	7 (6-7)
Cognitive deficits (MoCA)	18,8 (3-30)
Depression (HAM-21)	6,3 (0-32)
Caregiver burden (BSFC)	19,8 (0-47)
Stroke specialist recommendations	n (%)
Medical review	16 (44,4)
Change in medication	1 (2,78)
Rehabilitation or outpatient therapy	5 (13,9)
Referral for smoking cessation consultation	6 (16,7)
n recommendations per patient, median (IQR)	0,88 (0-2)

BI: Barthel Index; EQoL-5D EuroQuol; mRS: modified Rankin Scale; BP: blood pressure; IV: index value; VAS: Visual Analogue Scale; PSC: Post-Stroke Checklist; Morisky Adherence Scale; LAEB: Lisbon Aphasia Examination Battery; EAT: Eat Assessment Tool; FOIS: Functional Oral

Intake scale, HAM-21: Hamilton Depression Scale 21 Items; MoCA: Montreal Cognitive Assessment; BSFC: Burden Scale for Family Caregivers.

Discussion

Our small sample has been investigated for both objective and patient-perceived measures of long-term post-stroke burden. Similarly to previous studies, long-term post-stroke burden is particularly associated to cognitive decline and depression [22,37,38]. These health parameters were the most affected in patient-reported outcome measures and in validated clinical scales. Interestingly, patients in our sample had, on average, a long-term good motor outcome, with 91,7% of the patients categorized as independent after more than 3 years after stroke. Even though the mRS and BI scales are described in the literature as important predictors of quality of life, there is increasing evidence that these patients, whose post-stroke recovery appears complete, have difficulties with participation in social roles and difficulties in mental health and cognition [37,38]. Although, as previously mentioned, our assessment protocol was very similar to that carried out by the MAS-I team of researchers, our work stands out for focusing on a very specific stroke patient population (substantially different from that of the MAS- I): patients who underwent endovascular treatment in the acute phase, therefore representing an enormous investment (material and human resources, e.g) and that were classified as a short-term therapeutic success [22]. This is a population that intuitively seems to require a lower level of long-term care, as 91,7% of patients are autonomous in activities of daily living. Although we are not able to generalize our results with only thirty-six patients evaluated, this work is a reminder that this is also a subgroup of patients in which long-term care cannot be undervalued.

Despite the good therapeutic adherence, the 6% loss of medical follow-up is a concern, denoting the importance of establishing articulation strategies with primary health care providers. Compared to MAS-I, we found fewer patients with follow-up either in the general practitioner (69% in our cohort vs. 79% in MAS-I) or the neurologist (25% in our cohort vs. 40% in MAS-I) [22]. It may reflect differences between populations, namely in terms of less comorbidities and less insight into the need for follow-up, but it may also be due to cultural issues, difficulties in accessing medical care during the pandemic or due to the shortage of primary care professionals.

We also point out that even after more than 3 years of the stroke, additional therapeutic or etiological investigation measures were taken, reinforcing the need for individualized follow-up, without a pre-defined maximum follow-up time in a specialized cerebrovascular pathology consultation. Considering the most recent guidelines [39], several patients were recalled for reassessment and completion of the etiologic study, mainly concerning prolonged electrocardiographic monitoring in patients with undetermined etiology. We emphasize the need to review, at every moment, the indication to deepen the etiological investigation, in accordance with the most current recommendations. A multidisciplinary

assessment of the different domains can be time-consuming and difficult to routinely apply to the population that has suffered a stroke. Therefore, the ideal would be the application of a rapid screening test that would allow us to select the patients and the domains which need of reassessment [22].

Limitations of this study include the small sample size and survivor bias. Some patients refused to participate in the study due to the COVID-19 pandemic context during 2020 and 2021 and the apprehension of exposure to infection.

Conclusions

Even in a stroke population seen as a therapeutic success in the short-term, the impact of stroke transcends physical disability and unmet needs are observed in a range of health domains. To improve long-term stroke care it is certainly needed to apply more comprehensive patient assessment tools than the currently standard motor outcome scales. A standardized and multidisciplinary protocol in order to detect and manage post-stroke complications like anxiety, depression, fatigue, cognition, language, communication, swallowing or caregiver burden may represent an improvement in the quality of life of these patients. Our study reinforces that post-stroke follow-up time should be individualized. The timing of clinical discharge from a specialized consultation should not be pre-defined by a blindly applied protocol, but rather by the individual needs of each patient.

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