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## Post-stroke follow-up: time to organize

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## **ABSTRACT**

**Background/objective:** General practitioners (GPs) are pivotal in the organization of the entire post-stroke management system. This study aimed to examine the sequelae of chronic post-stroke patients and to assess whether the medical follow-up organized by GPs is truly in accordance with current recommendations and patients' clinical needs.

**Methods:** This was an observational study including chronic post-stroke patients after a first stroke. Their post-stroke follow-ups (visits to GPs and specialist doctors) were compared with guidelines and with clinical needs as evaluated through a number of questionnaires.

**Results:** Overall, 53.2% of patients visited a neurologist as recommended and, although 49.4% had neuropsychiatric consequences, only 6.3% visited a psychiatrist. Similarly, while 34.2% had significant post-stroke disability, only 6.3% saw a rehabilitation physician.

**Conclusion:** Taking into account not only cardiovascular prevention, but all post-stroke consequences, medical follow-ups as organized by GPs were not in accordance with recommendations and failed to take advantage of the currently available multidisciplinary resources required to improve patients' needs.

**Key words:** Stroke; General practice; Follow-up; Health resources; Neuropsychiatric impairment

## **INTRODUCTION**

Post-stroke patient follow-up is mandatory for optimizing secondary stroke prevention and identifying post-stroke physical, cognitive and neuropsychiatric complications, the major sources of disability and impaired quality of life in such patients [1]. International guidelines, including French ones, suggest standardized post-stroke management [2–5] to decrease the impact of post-stroke sequelae. In France as in many other countries, general practitioners (GPs) are the first point of contact with the healthcare system, and almost all patients follow a coordinated care pathway. Indeed, GPs provide primary care and have to organize referral to specialists when necessary [6] and, therefore, are supposed to gather together all patients' medical information.

While the role of GPs should be pivotal in post-stroke care [7], some differences may arise compared with stroke neurologists, and may provide a rationale for the assistance of networks involving multidisciplinary medical personnel. However, in several other countries, a few studies focusing only on secondary cardiovascular prevention have suggested that GP training and experience are less than optimal [8–13]. Post-stroke sequelae also extend to all other aspects of a patient's life, yet to our knowledge, only one previous study has focused on these other aspects, including disabilities and psychological impairment, and also explored GPs' perception of patients' disabilities in a small sample of patients with relatively mild complications. In fact, the authors suggested that this perception and patients' needs assessment by GPs are still lacking [14], making their prescribed management insufficient.

To optimize medical follow-up, French guidelines [4, 5, 15] recommend a visit to a GP within the first month of discharge from the stroke unit, and then every 3 months. In addition, they also recommend that GPs refer patients to specialized doctors to further assess and manage their health needs. Since 2003 (but actualized in 2007 and 2015) [4, 5, 15], these guidelines

have also recommended that patients systematically visit a neurologist within 6 months of having a stroke to optimize management of their post-stroke sequelae and treatment. Where necessary, they should also visit other specialists (such as cardiologists, rehabilitation specialists and/or psychiatrists) if specific cardiological, physical, cognitive and/or neuropsychiatric impairments are detected [4, 5, 15].

However, one important question that remains to be investigated is whether this entire system of post-stroke management and medical follow-up, as organized by GPs, is truly in accordance with the guidelines and make proper use of the currently available multidisciplinary resources. Thus, the present study aimed to compare the medical follow-up and paramedical care organized by GPs against patients' needs and current guidelines during the first post-stroke year.

## **METHODS**

This study enrolled patients 14 to 16 months after a first stroke between 1 October and 4 December 2013 in Southwest France as well as their GPs, and was part of a larger public-health program investigating post-stroke sequelae, patients' needs and quality of life. The protocols of both studies were approved by the ethics committee of our university.

Patients' inclusion criteria were: first ischemic or hemorrhagic stroke confirmed by neuroimaging and managed at a stroke unit; return to their usual place of residence at the time of evaluation; valid phone number recorded during the initial hospitalization; age > 18 years; and a GP willing to participate in a specific interview. All patients either had a scheduled visit with a neurologist or a recommendation to organize such a visit included in their hospital records for GPs. All GPs who agreed to participate had no specific requirements for inclusion.

Patients' exclusion criteria were: death before follow-up; and severe cognitive impairment or aphasia likely to impede their ability to answer questionnaires (by phone and posted mail).

To identify clinical needs, patients had to answer interviewer-administered questionnaires over the phone and to fill in self-administered questionnaires (in French, validated in a post-stroke population and with assistance in cases of motor impairment) sent through the post (with prepaid return envelopes). Interviewer-administered questionnaires assessed handicaps and disabilities using a modified Rankin Scale (mRS) score (0 = no handicap, 6 = dead) [16], and cognitive impairment using the French Modified Telephone Interview for Cognitive Status (TICS) with scores ranging from 0 to 43 (< 25 = cognitive impairment) [17]. Self-administered questionnaires evaluated measures of: health status using the EQ-5D-3L instrument, with scores ranging from 5 = no health problem to 15 = major health problem [18, 19]; social integration using the Community Integration Questionnaire (CIQ), with scores ranging from 0 = no integration to 29 = maximum integration [20]; limitations on activities of daily living (ADLs) using the Barthel index, with scores ranging from 0 to 100 (< 80 = limitations on ADLs) [21]; fatigue using the Fatigue Severity Scale (FSS), with scores ranging from 1 to 7 (> 5 = presence of fatigue) [22]; and anxiety and depression using the Hospital Anxiety and Depression Scale (HADS), with scores ranging from 0 to 42 (> 14 = symptoms of anxiety and depression) [23]. Initial stroke severity, as assessed by the US National Institutes of Health Stroke Scale (NIHSS) [24], was also recorded.

Patients' medical follow-ups were assessed by telephone interviews with their GPs, which were scheduled ahead of time to ensure access to patients' medical information and collected the following data: number of GP visits; reason for each visit; evaluations (organized or not by GPs) by specialists, including neurologists, cardiologists, rehabilitation physicians, geriatricians and/or psychiatrists, at least once within the post-stroke year. In addition, any

paramedical/rehabilitation care and follow-up involving a physiotherapist, nurse, occupational therapist, speech therapist and/or psychologist were also recorded.

In addition, specific characteristics of the participating GPs, such as age, number of years of medical practice, place of practice (rural, semirural, urban), and distance between the practice and the patient's home, were recorded.

The study first assessed the medical follow-up to determine whether it was in line with guidelines (for example, a GP visit during the first month after discharge from the stroke unit and then every 3 months, and a visit to a neurologist). Data from patients who had seen a neurologist were then compared with data from patients who had not, using Student's *t* test for quantitative data, chi-squared tests for qualitative data and Fisher's exact test for binary data. The same analyses were performed for patients who visited a cardiologist vs patients who did not. In addition, to determine whether healthcare resources were in line with patients' clinical needs, the same tests were used to compare physiotherapist and/or nurse follow-ups with patients' handicaps, limitations in ADLs and health status scores (mRS, Barthel index, EQ-5D-3L), and also speech therapist follow-ups and cognitive (TICS) scores. To compare the patients analyzed (whose GPs were willing to participate) with patients whose GPs were not, the same analyses were again performed to identify their clinical characteristics and needs. A *P* value < 0.05 was considered statistically significant.

## **RESULTS**

Of the 250 patients identified according to our inclusion/exclusion criteria, 79 answered the required questionnaires and had a GP willing to participate who could be contacted, and were analyzed for our study (Figure 1). No significant clinical differences ( $P > 0.05$ ) were observed between patients included in the analysis and those who returned questionnaires but whose

GPs were unwilling to participate (Table S1; see supplementary materials related to this article). Twelve GPs refused to participate or declared having no time to do so, two others were retired and 56 could not be reached after at least three attempts. The main clinical characteristics of the study population are summarized in Table 1. Overall, 22.7% of patients had limitations in ADLs (Barthel index scores < 80), 34.2% had moderate or severe disability requiring help (mRS scores > 2), 20.3% had cognitive impairment (TICS scores < 25), 45.6% had post-stroke fatigue (FSS scores > 5) and 49.4% had neuropsychiatric consequences with anxiety and/or depression (HADS scores > 14).

Regarding medical follow-ups, only one patient failed to visit a GP within the first month of discharge from the stroke unit and then every 3 months. The median number of visits with a GP was 10 [interquartile range (IQR): 7–16]. The main reason for these visits was related to stroke follow-up (96.2%), including cardiovascular prevention. As for follow-ups by a specialist, only 42 patients (53.2%) saw a neurologist, as recommended by guidelines. In addition, 66 (83.6%) visited a cardiologist, 35 (44.3%) saw both a neurologist and a cardiologist; five (6.3%) visited a rehabilitation physician, four (5.1%) visited a geriatrician and five (6.3%) saw a psychiatrist.

Patients who saw a neurologist had significantly more disability, as assessed by their mRS scores ( $P = 0.019$ ), and poorer health status, as assessed by the EQ-5D-3L ( $P = 0.049$ ). No significant association was observed with any other variables (Table 2). In fact, the only variable significantly associated ( $P = 0.016$ ) with visiting a cardiologist was gender, with men being more frequently evaluated than women (Table S2; see supplementary materials related to this article).

Regarding paramedical care, 35 patients (44.3%) were followed-up by a physiotherapist, 21 (26.6%) by a speech therapist, six (7.6%) by a psychologist, three (3.8%) by an occupational



therapist and 23 (29.1%) by a nurse. The main reasons for nursing care were assistance/initiation of treatment (80%), and a need for nursing and hygiene care (65.2%).

A total of 15 GPs reported difficulty organizing a visit with a specialist due to a poor medical network, and six reported limited access of their patients to physiotherapy and/or speech therapy at home. Of these GPs' patients, 12 (80%) had a follow-up with a neurologist and 12 (80%) saw a cardiologist; however, every patient with a Barthel index score < 80 benefited from physiotherapy.

Patients receiving nursing care had significantly more disability, more limitations in ADLs and poorer health status as assessed by mRS ( $P < 0.001$ ), Barthel index ( $P < 0.001$ ) and EQ-5D-3L ( $P < 0.001$ ) scores, respectively, compared with patients followed by a physiotherapist. Finally, speech therapist interventions were not significantly associated with cognitive impairment, as assessed by TICS scores ( $P = 0.893$ ). These results are presented in Table 3.

## **DISCUSSION**

This 1-year study of medical post-stroke management identified three main results: (i) the frequency of GP evaluations was in accordance with current recommendations; (ii) neurologists are still insufficiently involved in stroke follow-up despite recommendations; and (iii) there is still a gap between patients' needs and currently available multidisciplinary resources, such as specialists like rehabilitation physicians, psychiatrists and speech therapists.

In addition, our present study has indicated that only half of these stroke patients were evaluated by a neurologist as recommended for post-stroke management. This lack of adherence to guidelines is evidently not influenced by limited access to specialists, given the

higher rate of recommended follow-ups for these patients in their GP reports, nor by any bias of our GP sample, whose characteristics were similar to those of other GPs in the area [25]. Post-stroke evaluation by a neurologist has several objectives, including optimizing pharmacological and non-pharmacological secondary prevention, evaluating stroke mechanisms, and detecting the presence of physical complications, cognitive impairment and neuropsychiatric complaints. However, it is also of particular importance because GPs' perceptions of their patients' disabilities are still inadequate [14].

Indeed, the present findings demonstrate that patients followed by neurologists have higher levels of residual physical handicap, whereas no differences in cognitive and neuropsychiatric complications were observed. This suggests that physical disability is still given more consideration than 'invisible' psychoemotional handicaps. Moreover, these patients were only marginally followed by rehabilitation physicians even though more than one in five had significant residual physical disability. Likewise, despite almost half the patients having significant anxiety or depressive post-stroke complications, referral to a psychiatrist was only marginal, again suggesting the insufficient medical follow-up of these patients.

These findings highlight how underestimated neuropsychiatric post-stroke complications are, even though they are well known to impair post-stroke rehabilitation and quality of life [26]. Moreover, it is surprising to see that patients with cognitive impairment are not significantly more often followed-up by a speech therapist, despite speech therapy being a first-line treatment for post-stroke cognitive/language disorders in ambulatory care.

Regarding secondary cardiovascular prevention, even though this was not explored directly, our results suggest that this is the focus of most GPs, given the high rate of scheduled follow-ups with a cardiologist (> 80%). Secondary cardiovascular prevention is an important part of the national guidelines; as GPs are aware of this, they optimize medical treatments according

to the rules of cardiovascular risk management, and some studies currently underway are exploring the efficiency of such management by GPs [27]. However, there are data to suggest suboptimal secondary prevention of high blood pressure and cholesterol, and less use of oral anticoagulation when follow-up is by GPs alone [8–13]. Thus, it is likely that collaborations between GPs and specialized resources (such as stroke neurologists and cardiologists) for more complex cases and the provision of clear individualized guidelines could ensure improvement of long-term follow-ups.

Nevertheless, the results of our present study need to be interpreted cautiously due to the small sample size and the inclusion of patients who returned to their places of living after their stroke. Moreover, visits scheduled by the GP but not carried through by the patient were not taken into account. While the consequences would remain the same—the provision of less-than-optimal post-stroke management—the causes would be different. Thus, the attitude and involvement of post-stroke patients also need to be improved through therapeutic education programs to further prevent inefficient post-stroke management.

## **CONCLUSION**

Our present study findings suggest that GPs are mostly focused on dependence/motor impairment and cardiovascular secondary prevention while apparently underestimating cognitive/emotional impairments, as also noted for patients with transient ischemic attacks [28]. GPs will continue to play an important role in the proximity care of post-stroke follow-up and cardiovascular prevention; however, they should also receive regular training in the detection of ‘invisible’ post-stroke complications. This points to the importance of strengthening the entire healthcare network and creating multidisciplinary teams involving different contributors to post-stroke management. Although the conclusions of the present

study are in line with the latest recommendations of the French Healthcare System to create such multidisciplinary teams and to schedule each patient for a multidisciplinary consultation [29], in the face of the low rate of patients who actually visited a neurologist, applying these recommendations still requires hard work to optimize their intended results.

#### **Declaration of conflicts of interest**

The authors declare no conflicts of interest

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Table 1 – Characteristics of the analyzed patients and their general practitioners.

<b>Patients (n = 79)</b>	<b>Clinical measures</b>
Age, mean (SD)	71 (11.4)
Women	28 (35.4%)
Ischemic stroke	68 (86.1%)
Initial stroke severity score (NIHSS)	3 (2–8.25)
Barthel index	100 (80–100)
Modified Rankin Scale score	2 (1–5)
Fatigue Severity Scale score	4.8 (3.4–5.9)
Hospital Anxiety and Depression Scale score	16 (11–19)
Community Integration Questionnaire score	13 (5–27)
EQ-5D-3L score*	6.9 (5.8–10.5)
Modified Telephone Interview for Cognitive Status score	31 (26–43)
<b>General practitioners (GPs)</b>	
Age, mean (SD)	54.7 (10.5)
Women	17 (21.5%)
Place of practice (urban/semirural/rural)	33/25/21
Distance in km between GP office and patient's home	2 (1–4)
Number of years in medical practice	27 (18–34)

Data are medians (interquartile range) or n (%) unless otherwise specified;

\* measure of health status;

SD: standard deviation; NIHSS: National Institutes of Health Stroke Scale.

Table 2 – Association between patients’ clinical measures and follow-up with a neurologist or not.

	Neurologist visit (n = 42)	No neurologist visit (n = 37)	<i>P</i> *
Age, mean (SD)	72 (11.6)	70.1 (11.3)	0.477
Women	15 (35.7%)	13 (35.1%)	0.538
Ischemic stroke	33 (78.6%)	35 (94.6%)	0.082
Initial stroke severity score (NIHSS)	3 (1.5–9)	3 (2–6)	0.673
Barthel index	100 (75–100)	100 (85–100)	0.277
Modified Rankin Scale score	2 (1–3)	1 (1–2)	0.019
Fatigue Severity Scale score	4.6 (3.4–6.3)	4.9 (3.5–5.8)	0.768
Hospital Anxiety and Depression Scale score	16 (12–18)	16 (8–20)	0.531
Community Integration Questionnaire score	11 (4–17)	14.5 (9.25–18)	0.176
EQ-5D-3L score**	9 (6–10)	7 (6–9)	0.049
Modified Telephone Interview for Cognitive Status score	31 (26.5–34.5)	30.5 (24.75–35.25)	0.841

Data are medians (interquartile range) or n (%) unless otherwise stated; \* by Student’s *t* test for quantitative data, Fisher’s exact test for binary data; \*\* measure of health status;

SD: standard deviation; NIHSS: National Institutes of Health Stroke Scale.

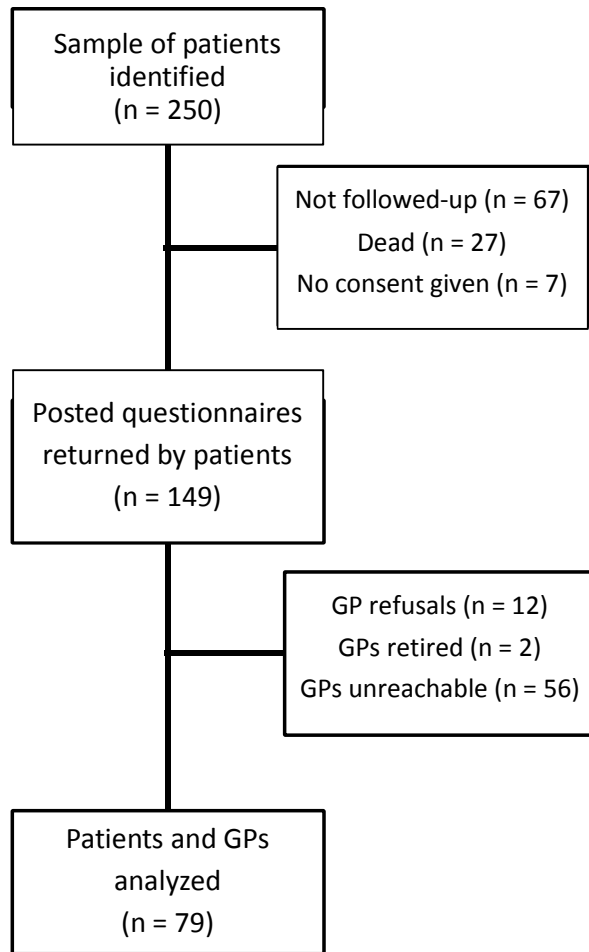


Table 3 – Association between paramedical care (follow-up by physiotherapist, nurse, speech therapist) and patients' clinical measures.

	Physiotherapist			Nurse			Speech therapist		
	Yes (n = 35)	No (n = 44)	<i>P</i> *	Yes (n = 23)	No (n = 56)	<i>P</i> *	Yes (n = 21)	No (n = 58)	<i>P</i> *
Age, mean (SD)	73.7 (11.3)	68.8 (11.3)	0.062	75.3 (10.6)	69.2 (11.5)	0.033	69.5 (12.0)	71.5 (11.4)	0.499
Barthel index	80 (55–100)	100 (95–100)	< 0.001	75 (50–88.75)	100 (95–100)	< 0.001	97.5 (70–100)	100 (82.5–100)	0.009
mRS score	3 (2–4)	1 (0–1.75)	< 0.001	3 (2–4)	1 (0–2)	< 0.001	2 (1–3.25)	1 (0–2.5)	0.005
FSS score	51 (33–57)	41 (27.5–51.75)	0.107	52.5 (34.5–57.75)	41 (27–52)	0.081	42.5 (26.5–51.75)	43 (32.5–56)	0.748
HADS score	2 (1–2)	1.5 (1–5)	0.154	1 (1–2)	2 (1–5)	0.01	1 (1–2)	2 (1–4.5)	0.141
CIQ score	6 (4–13)	16.5 (12.25–19.75)	< 0.001	4.5 (3.25–11)	16 (11–19)	< 0.001	13.5 (7.5–18)	14 (6–18.5)	0.201
EQ-5D-3L** score	9 (7–11)	6 (5.25–9)	< 0.001	10 (9–12)	7 (6–9)	< 0.001	8 (6–10.5)	7 (6–9)	0.011
Modified TICS score	29 (22–32)	34 (30–36.75)	0.002	25 (19–29.75)	33 (29–36)	< 0.001	29.5 (22–34.25)	31 (27–36)	0.893

Data are medians (interquartile range) or n (%) unless otherwise specified; \* by Student's *t* test; \*\* measure of health status;

SD: standard deviation; mRS: modified Rankin Scale; FSS: Fatigue Severity Scale; HADS: Hospital Anxiety and Depression Scale; CIQ: Community Integration Questionnaire; TICS: Telephone Interview for Cognitive Status.



**Fig. S1 – Flow chart of patient and general practitioner (GP) recruitment into the study.**