

## **Original Article**

# Individualized home-based rehabilitation after stroke in France: a pragmatic study of a community stroke rehabilitation team

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**ABSTRACT:** *Background:* Community stroke rehabilitation teams (CSRT) provide an individualized home-based rehabilitation service to patients recovering from stroke. *Objective:* To examine whether there is an improvement in the social participation of patients who received a rehabilitation program provided by CSRT. The secondary objectives were to show if there is an improvement in the patients' quality of life and a reduction in the caregiver burden. *Methods:* Retrospective cohort study, pragmatic in real-care conditions. The rehabilitation program delivered by the CSRT was adapted to the needs of the patients and caregivers. The outcome questionnaires included: the Frenchay Activity Index (FAI), the Minizarit, the EuroQol EQ5D, and the Barthel Index. The primary outcome measure was the FAI. *Results:* We included 206 patients followed by the CSRT over the 2018–2020 study period, for whom the primary endpoint was present. The mean age was  $66.3 \pm 12.7$  years, the post-stroke delay was  $16.4 \pm 32.7$  months, and the Barthel index was  $66.42 \pm 12.6$ . The duration of the rehabilitation program was on average  $162 \pm 109$  days. We observed a significant improvement in the FAI, from  $12.9 \pm 10.4$  to  $17.85 \pm 12.4$  (p < 0.00001); in the EuroQol, from  $57.51 \pm 19.96$  to  $66.36 \pm 18.87$  (p < 0.00001); in the mini-Zarit, from  $2.49 \pm 1.75$  to  $2.06 \pm 1.67$  (p = 0.0002); and in the Barthel index, from  $66.42 \pm 12.67$  to  $84.81 \pm 23.70$  (p < 0.0001). *Conclusion:* Patients who received a rehabilitation program by the CSRT have an improvement in their social participation, and their informal caregivers have a reduction in their burden.

**RÉSUMÉ :** Programme de réadaptation individualisée à domicile après un accident vasculaire cérébral, en France : étude pragmatique d'une équipe communautaire de réadaptation après un AVC. Contexte : Des équipes communautaires de réadaptation après un accident vasculaire cérébral (ECRAVC) offrent des services de réadaptation individualisée à domicile à des patients ayant subi un AVC. Objectifs : L'étude visait principalement à examiner si le fait suivre un programme de réadaptation offert par les ECRAVC permettait d'améliorer la participation sociale des patients. Elle avait aussi pour objectifs secondaires de vérifier si le programme se traduisait par une amélioration de la qualité de vie des patients et une diminution du fardeau des aidants. **Méthode :** Il s'agit d'une étude de cohortes, rétrospective, pragmatique, réalisée dans des conditions réelles de prestation de soins. Le programme de réadaptation fourni par les ECRAVC était adapté aux besoins des patients et des aidants. Les questionnaires sur les résultats comprenaient l'index d'activités de Frenchay (IAF), la mini-grille de Zarit, l'EuroQol EQ5D et l'index de Barthel. Le principal critère d'évaluation était l'IAF. **Résultats :** Ont participé à l'étude 206 patients suivis par les ECRAVC, sur la période d'étude de 2018 à 2020, chez qui pouvait être mesuré le principal critère d'évaluation. L'âge moyen était de  $66,3\pm12,7$  ans; le temps écoulé depuis l'AVC, de  $16,4\pm32,7$  mois; l'index de Barthel, de  $66,42\pm12,6$ . La durée du programme de réadaptation s'élevait en moyenne à  $162\pm109$  jours. Une amélioration sensible a été observée aux différentes mesures de résultats : l'IAF, de  $12,9\pm10,4$  à  $17,85\pm12,4$  (p<0,00001); l'EuroQol, de  $57,51\pm19,96$  à  $66,36\pm18,87$  (p<0,00001); la mini-grille de Zarit, de  $2,49\pm1,75$  à  $2,06\pm1,67$  (p=0,0002) et l'index de Barthel, de  $66,42\pm12,67$  à  $84,81\pm23,70$  (p<0,0001). **Conclusion :** Le programme de réadaptation offert par les ECRAVC s'est traduit par une amélioration de la participation sociale des patients

Keywords: Rehabilitation; Home; Participation; Burden

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#### Introduction

Stroke is the leading cause of acquired neurological disability. In France, it is estimated that approximately 750,000 people have survived a stroke, 60% of whom still have sequelae (motor deficit,

language disorders, cognitive disorders, sensory, or visual disorders, etc.).

In France, after hospitalization in an acute unit, 36% of patients receive inpatient rehabilitation (23.4% in general or geriatric

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rehabilitation center and 10.4% in neurological rehabilitation center) for an average of 46 days. Returning home allows the subject to be reintegrated into their environment in a real-life situation. It is at this moment that the patient and their relatives truly become aware of the restriction in social participation linked to sequelae. This restriction of the patient's participation is linked partly to the severity of the stroke and the sequelae that limit activities<sup>2,3</sup> and partly to contextual factors such as adaptations to the living environment, and especially social support. For the return home, the support of relatives is essential, allowing better social participation, 4-6 but it can lead to exhaustion, the patient's difficulties being seen as a burden.

After returning home, patients experience a breakdown in care and follow-up.<sup>7</sup>

A systematic review by Chen et al. in 2019 showed that 73% of patients report at least one essential need not taken into account that would facilitate their daily life at home, and generally between two and five. These needs most often related to impairments and activity limitations (59.7% to 83.7%). They also requested assistance in facilitating mobility in the community (transportation, etc.) (5.4% to 53%) and assistance in the home and personal care (4.7% to 39.3%). Finally, they reported a lack of information on their illness and its sequelae (3.1% to 65%). A study measuring the perceived state of health over the 5 years following stroke in a cohort of 2190 patients identified unmet care needs as one of the main determining factors, with an odds ratio of 0.39 at 1 year, 0.49 at 3 years, and 0.32 at 5 years.

In order to avoid this disruption and ensure continuity of care, the rehabilitation program must continue at home, taking into account the contextual factors. 7 It is in this context that community stroke rehabilitation teams (CSRT) were created to facilitate the implementation of home-based rehabilitation programs. Four types of CSRT have been identified in the literature: 1) intra-hospital teams for occasional advice and referral of patients to the various acute care departments; 2) teams for early supported discharge; 3) teams for post-discharge community rehabilitation; 4) teams for late community rehabilitation, for chronic patients with sequelae. In France, Regional Health Agencies (RHA) promote the development of CSRT corresponding to types 3 and 4, allowing delivery of a home-based rehabilitation program and coordination of care. These teams make it possible to respond to unmet needs in patients who are often in great difficulty (in particular, patients with the invisible handicap caused by cognitive disorders). 10 A few studies 10,11 seem to show that these CSRT could have a lasting impact on the social participation of patients and on the caregiver burden.

In particular, Allen et al.,  $^{10}$  published the only study to our knowledge on the evaluation of this type of CSRT. This was a pragmatic noncontrolled study conducted on subacute patients in Canada. Their results showed that the intervention improved social participation and reduced the caregiver burden. The Reintegration into Normal Living Index (RNLI) questionnaire progressed from 15.69 ( $\pm 4.7$ ) to 18.20 ( $\pm 4.1$ ) (p = 0.01) and at the same time, the Caregiver Assistance and Confidence Scale CACS decreased from 39.96 ( $\pm 25.9$ ) to 28.82 ( $\pm 22.0$ ) and the Bakas Caregiver Outcome Scale (BCOS) went from 48.97 ( $\pm 8.7$ ) to 53.73 ( $\pm 11.5$ ) (p = 0.005).

The main objective of this work was to examine whether there is an improvement in the social participation of post-stroke patients (on the subacute and chronic phase) who received a rehabilitation program provided by CSRT. The secondary objectives were also

to show an improvement in the patients' quality of life and a reduction in the caregiver burden.

#### **Methods**

#### Type of Study

This is a retrospective cohort study, pragmatic in real-care conditions, without control group, received French official authorizations and was approved by the local ethics committee (CCTIRS No.14.395bis and CNIL No. 914581), in accordance with Helsinki declaration. All the patients have given their informed consent for participation in the research study.

#### **Population**

The eligibility criteria for participating in the program were: having had a stroke, regardless of the nature and date of the stroke, having returned home, encountering difficulties in everyday life, residing in the region, Haute Vienne department and having signed the consent form. Patients, their families, or caregivers working at home can contact the CSRT to enter the program. Inclusion is made after acceptance by the family doctor, who participates in the development of objectives and validates the rehabilitation program.

#### **CSRT Program and Database**

The home-based rehabilitation took place under the guidance of the CSRT. The CSRT includes a part-time rehabilitation medicine doctor, neuropsychologist, occupational therapist, and physical activity teacher, as well as a full-time nurse coordinator. A first interview with the coordinating nurse and/or doctor allowed defining the home-based rehabilitation objectives and the implementation of the program. Several home visits were organized according to identified needs, as well as a weekly multidisciplinary meeting. The home visits were based on an individualized task-specific approach. Patients specified concrete tasks that they wished to carry out with the professional, and the personal or physical barriers that hampered their actions. Home-based rehabilitation provides services to help these individuals achieve social participation in their current living environment.

If they agreed, patients and their families benefited from the care education program authorized by the HRA. This program includes workshops focused on the management of sequelae (cognitive and communication disorders, mobility, physical activity, falls, pain, treatment).

The different interventions have been listed according to the International Classification of Functioning disability and health (ICF). The interventions differed significantly from one situation to another and concerned mostly participation, social mobility, community life, social support, and relationships, including education about care and a supervised physical activity program.

The CSRT also had the role of coordinating care with professionals in the community (physiotherapists, social workers, etc.). The duration of the program varied according to the needs identified. Medical, socio-familial and administrative data were collected from the patient and family and from the medical file during the initial interview. They included the nature and duration of the stroke, contextual factors (place of residence and the existence of an informal caregiver), and impairments and activity

limitations (as assessed by the Barthel index).<sup>12</sup> The team members entered all information in the database.

#### **Outcome Measurements**

Questionnaires were first administered during the initial visit and then at the end of the CSRT intervention.

The Frenchay Activity Index (FAI): Social participation was assessed with the FAI, developed by Holbrooke and Skilbeck, <sup>12</sup> then modified by Wade et al. It is made up of 15 items assessing the frequency of activities in three areas: daily life, leisure/work, and outdoor activities. Each item is scored between 0 (never) and 3 (frequently). The difference between the two versions involves the scoring system, which went from 1–4 to 0–3.

The MiniZarit: The caregiver burden was assessed with the Minizarit in its 7-item version as described by Gort et al.<sup>13</sup> The caregiver determined how often they experience different emotions in their relationship with the patient, on a scale of 0 to 4 (never to almost always). The 7-item version is a good compromise between speed of execution and correlation with the 22-item Zarit.<sup>14</sup> A high score indicates a heavy burden.

The Euroqol: Quality of life was assessed with the EuroQol in its 5D version.  $^{14,15}$  We chose to use the visual analog scale of the EuroQol to facilitate use. Its use is validated for stroke.  $^{16-18}$ 

#### **Statistical Analysis**

We reported the mean and the standard deviation for the quantitative variables with normal distributions, and the median and interquartile range (IQR) for the quantitative variables with non-normal distributions. The normality of the variables was assessed using the Shapiro–Wilk test.

We performed a comparison of means between the values of the initial and final assessments of the FAI, MiniZarit, and EuroQol. The statistical tests used depended on the normal or non-normal distribution of variables. For a normal distribution, we used Student's *t* test for paired samples. For a non-normal distribution, we used the Wilcoxon test for matched samples.

For all statistical analyses, the alpha risk was 0.05. Statistical analyses were performed using R software version 3.6.3 (2020-02-29), packages "questionr", "tidyverse", and "car".

## Results

#### **Population**

Of the 279 patients treated by the CSRT over the 2018–2020 study period, we only included in the analysis the 206 patients for whom the primary endpoint was present. There did not appear to be any difference between included and non-included patients when comparing existing data. The inclusion description of the patients studied is given in Table 1.

The characteristics of the home-based rehabilitation program and CSRT interventions are shown in Tables 2 and 3. The median duration of the program was  $145 \pm 75$  days.

Seventy percent of patients and their relatives received the care education program authorized by the RHA.

In addition to interventions by the CSRT, the program also included the interventions of community physiotherapists and speech therapists. The patients included in the program received an average of 1.3 (±1.2) physiotherapy sessions per week.

We observed a significant improvement between the beginning and the end of the rehabilitation program provided by the CSRT in the FAI, from 12.9 ( $\pm 10.4$ ) to 17.85 ( $\pm 12.4$ ) (p < 0.00001); in the

Table 1: Description of the study population

Characteristics of the population	Number (%)	
Sample	206	
Female gender	69 (33)	
Married	122(59)	
Children at home	32(16)	
Children nearby	8(4)	
Caregiver at home	136(66)	
retired	138(67)	
Ischemic stroke	162(79)	
First stroke	158(77)	
Sub-acute stroke	180(64.7)	
Left hemispheric lesion	108(52)	
Aphasia	90(44)	
Unilateral neglect	34(17)	
Cognitive disorders	128(62)	
Urinary disorders	29(14)	
Post stroke depression	59(29)	
Motor deficit	120(58)	
	Mean (±SD)	
Post stroke delay in months	16.4 (±32.7)	
Age in years	66.3 (±12.7)	
Barthel index /100	62.42 (±12.7)	
Referral source	Number (%)	
Patient / family (community)	41(20)	
Rehabilitation unit	88(43)	
Neurological unit	34(17)	
Other / community	43(20)	
- Carter / Community	.5(25)	

mini-Zarit, from 2.49 ( $\pm$ 1.75) to 2.06 ( $\pm$ 1.67) (p < 0.001); in the EuroQol, from 57.51 ( $\pm$ 19.96) to 66.36 ( $\pm$ 18.87) (p < 0.00001); and in the Barthel index, from 66.42 ( $\pm$ 12.67) to 84.81( $\pm$ 23.70) (p < 0.001) (Figure 1).

### **Discussion**

Our study shows that post-stroke patients who received individualized home-based rehabilitation delivered by CSRT have their social participation improved and the burden on their caregiver decreased. Our results confirm those reported by Allen et al., 10 who published the only study to our knowledge on the evaluation of this type of CSRT. This was a pragmatic non-controlled study conducted in Canada. The team intervention improved impairments and activity limitations during the program, which might be expected, but maintenance of this benefit was also observed 6 months after stopping the program. Further, their results showed that the intervention improved social participation and reduced the caregiver burden. These results are confirmed by our study. Even if the results of the two studies point in the same direction, it is difficult to compare the results. The common point of the rehabilitation programs of the two studies is that they are individualized with specific objectives that differ from one patient to another. As a result, the nature of the actions and the duration of the care are

Details of intervention per patient per entire program duration	Number of visits Mean (±SD)	Total duration of visits in minutes Mean (±SD)
Doctor	0.73 (±0.77)	89 (±99)
Nurse	1.45 (±1.61)	206 (± 226)
Occupational therapist	1.43 (±2.02)	199 (± 239)
Neuropsychologist	1.02 (± 1.18)	145 (±166)
Adapted physical activity teacher	1.13 (± 1.51)	132 (±172)
Total CSRT visits	4.55 (± 3.31)	605 (±465)

Table 2: description of home visits by the CSRT to which is added the physiotherapy and speech therapy sessions not delivered by the CSRT

**Table 3:** Interventions of the rehabilitation program provided by the CSRT adapted to the individual needs, categorized according to the domains of the ICF

Domains of intervention categorized according to ICF	Number of patients	%
Activities and participation	184	98
Chap 4 Mobility	166	88
Chap 9 Community, social and civic life	104	55
Chap 2 General tasks and demands	139	74
Chap 6 Domestic life	58	31
Chap 7 Interpersonal interactions and relationships	56	30
Chap 3 Communication	63	34
Chap 5 Self-care	12	6
Environmental factors	118	63
Chap 3 Support and relationships	118	63
Chap 1 Products and technology	15	8
Chap 4 Attitudes	23	12

very different from one situation to another in each of the studies. The great diversity of needs makes the description of actions and the standardization difficult. It is probably this common character of individual specificity which is the main element of the effectiveness of the programs. These results illustrate the fact that through the home intervention, actions which are adapted to the living environment make it possible to act on social participation and on the caregiver burden. Our results show that this type of CSRT seems adapted to the French health care system. In addition, Allen's study<sup>10</sup> shows a maintenance of the gain 6 months after the end of the intervention, which attests to a change in lifestyle. The same authors, on a larger enriched cohort, have shown that patients living in rural areas derive the same benefit as subjects living in urban areas.<sup>19</sup> They therefore conclude that CSRT are an interesting alternative for the care of patients in isolated rural areas.

The rehabilitation program proposed by our CSRT was individualized and adapted to the needs of each patient. Our program most often included interventions in the areas of participation (98%), social mobility (88%), community life (55%), social support and relationships (63%), and care education (70%).

In our study, the objective of improving mobility concerns 88% of patients. For it, the physical activity teacher offers a program to improve community ambulation consisted of walking practice in a variety of settings and environments in community or an indoor activity in social situation. This program is not specific for post-stroke patients and is therefore complementary to specific

physiotherapy treatment. We know that mobility is a key factor in social participation.<sup>2</sup> This intervention could be partly at the origin of the improvement in the social participation of patients even if for the moment there is not a significant level of proof on the effectiveness of these interventions.<sup>20</sup>

If we compare our results with the data in the literature, we observe that we intervened in the difficulties most often reported by patients at home. Indeed, a Swedish qualitative study<sup>21</sup> collected the experience of patients supported by this same type of CSRT. In this study, five main objectives of home rehabilitation identified by patients emerge: (i) develop learning strategies to solve problems in daily activities at home and in the community; (ii) receive a supervised exercise program; (iii) explore community services and facilities; (iv) have a dialog with professionals; and (v) engage in returnto-work activities. The implementation of home-based rehabilitation activities appeared to enhance participants' active participation and ability to set goals for their recovery and to assess them themselves.<sup>21</sup> The systematic review of Chen et al.<sup>8</sup> also showed that these patients are asking for help to facilitate mobility in society (transportation) (5.4% to 53%) and to benefit from appropriate treatment and home aid (4.7% to 39.3%).

We have shown in our study, just like Allen et al., <sup>10</sup> that home-based rehabilitation provided by a CSRT can reduce the caregiver burden. The role of parents and relatives is essential, as positive support allows better functional recovery and better participation. <sup>7,8,22</sup> This strong support can generate a feeling of exhaustion,

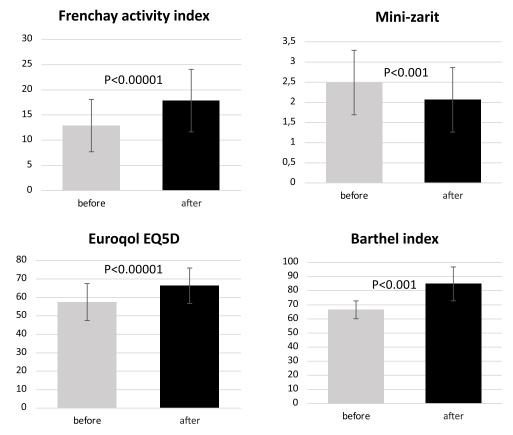


Figure 1: Evolution of outcomes between the start and the end of the home-based rehabilitation program provided by the CSRT.

the dependence of the patient being experienced as a burden. An important part of our rehabilitation program was care education and counseling for patients and relatives. Our study design is not randomized controlled, so it is not possible to assert that the observed changes are related only to the intervention. But we also know that the burden of caregivers does not spontaneously progress favorably in the first years after stroke, and seems on the contrary to worsen.<sup>23</sup> We therefore propose that in our study, the reduction of the burden is very probably linked to the homebased rehabilitation delivered by the CSRT. According to studies, up to 65% of patients report a lack of information about their disease and its sequelae (3.1% to 65%). In our study, 70% of patients expressed the need to receive more education. A survey of 100 informal caregivers showed that therapeutic education reduces the burden (as assessed by the Zarit scale / 88) and improves their quality of life (as assessed by SF-36).<sup>24</sup> In this study, the burden decreased from 67.8 to 41.5 in the education group and remained stable in the control group at 61. This study concluded that family education should be a priority in care. These elements make us think that education about the care of the patient and their family was a determining element in the reduction of the burden.

The main strength of our study is that it is a pragmatic study in real-care situations about CSRT as proposed in the French health-care system. This makes it possible to evaluate the functioning and effectiveness of the CSRT in a real situation and not in an experimental situation. We know that the results can be quite different between experimental and pragmatic studies, but it appears necessary to carry out these pragmatic studies to validate current care organization models. Another strong point of our study is to have

shown a beneficial effect in chronic patients. For comparison, the population studied by Allen, who had found a positive effect was on average 3 months from the stroke, while our patients are at 16 months from stroke. The majority of the stroke rehabilitation literature focuses on interventions in the first-year post-stroke when expected improvements are greatest, so it is therefore very remarkable to have been able to demonstrate improvements in social reintegration in chronic patients over 1-year post-stroke.

A limitation of our study is its retrospective nature, with a number of missing data, but the total number of patients is significant. Another limitation is the fact that the rehabilitation program is not standardized but individualized to each patient. The great diversity of needs makes the description of actions difficult. Therefore, it is difficult to globalize the results. Likewise, the duration of the rehabilitation program varied greatly from one patient to another. Finally, the study design is not randomized controlled, so it is not possible to assert that the observed changes are related only to the intervention. However, as we have seen in the discussion, some results suggest a real effectiveness of the home-based rehabilitation delivered by the CSRT.

#### **Conclusion**

Our study shows for the first time in France that post-stroke patients who receive home-based rehabilitation by CSRT have an improvement in their social participation, both in the chronic phase and in the subacute phase. In the same time, their informal caregivers have a reduction in their burden. This pragmatic study in routine care highlights the benefits of CSRT in the French

healthcare system. Further study will be necessary to show sustained benefits post intervention in a long-term follow-up.

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#### Conflict of Interest. None.

**Statement of Authorship.** JCD: writing the protocol, building the database, writing the article; DB: writing the protocol, data collection, reviewing the article; MC: building the database, statistical analysis, reviewing the article; GB: data extraction and writing the article; LM: data extraction and writing the article; JYS: writing the protocol and reviewing the paper

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