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ORIGINAL RESEARCH

Determinants of Social Participation at 1, 3, and 6 Months Poststroke in Benin

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Abstract

Objective: To build a model of prediction of social participation of community-dwelling stroke survivors in Benin at 1 month, 3 months, and 6 months.

Design: An observational study with evaluations at 1 month, 3 months, and 6 months poststroke. Correlational analyses and multivariate linear regressions were performed.

Setting: Outpatient rehabilitation centers in Benin.

Participants: A volunteer sample of 91 stroke patients was enrolled at baseline; 64 (70%) patients completed all the study (N = 64): 70% male and 52% right hemiparesis.

Intervention: Not applicable.

Main Outcome Measures: Participants were evaluated with the Participation Measurement Scale, ACTIVLIM-Stroke (activities of daily living [ADL]), Stroke Impairment Assessment Set, 6-minute walk test, Hospital Anxiety and Depression Scale, and the modified Rankin Scale.

Results: The significant predictors of social participation after controlling the confounders were the following: at 1 month ADL (0.4 [0.3, 0.6]) and depression (–0.6 [–0.8, –0.2]) with total model $R^2 = 0.44$; at 3 months ADL (0.58 [0.4, 0.7]) and depression (–0.58 [–0.5, –0.7]) with total model $R^2 = 0.65$; and at 6 months ADL (0.31 [0.2, 0.5]), impairments (–0.82 [–0.5, –0.7]), and depression (–0.94 [–0.8, –0.2]) with total model $R^2 = 0.78$.

Conclusions: Using socioculturally tailored tools, the present study identified ADL performance (ACTIVLIM-Stroke), depression (Hospital Anxiety Depression Scale), and overall impairments (Stroke Impairment Assessment Set) as the significant determinants of social participation (Participation Measurement Scale) poststroke in Benin. These findings will be a valuable resource for rehabilitation stakeholders in evaluating interventions, programs, and policies designed to encourage social participation for stroke patients.

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Poststroke functional recovery is a complex process that typically evolves over time.[1-4] During the early recovery months, stroke survivors have to cope with various physical, functional, and social challenges that involve activity limitations and participation restrictions consequent to stroke.[4-7] Specifically, some studies found that social participation within the first 3 months of discharge is very often low, with significant increases over the next few months.[8,9] Several instruments have been designed to evaluate body functions and structures,[10,11] activities,[12-14] and participation poststroke.[15-18] Recently, the Participation Measurement Scale (PM-Scale) was developed to measure participation poststroke in African contexts.[15,19] It offers clinicians and researchers in Africa an interesting opportunity to better evaluate stroke survivor participation.

The challenges experienced by stroke patients after being discharged can be conceptually described within the World Health Organization's framework of International Classification

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of Functioning, Disability and Health. Rehabilitation poststroke has been found to be beneficial in facilitating recovery and improving social participation and quality of life.[20,21] To our knowledge, no published literature is available about the rehabilitation services provided to stroke patients in Benin. Overall, in Benin as in many developing African countries, the availability of rehabilitation services is poor and inadequate.[22,23] The majority of stroke patients receiving outpatient rehabilitation often receive between 2-3 physiotherapy sessions per week over a 6-month period, each session lasting 30-60 minutes.[4] Stroke patients who are admitted to inpatient rehabilitation facilities also have limited follow-up treatment and contact with a physiotherapist, although they could benefit from these services.[24] Almost all stroke patients in Africa return to their communities and live at home after being discharged from the hospital.[25-28] Therefore, interventions during stroke rehabilitation should seek to promote good community reintegration and participation as early as possible in such patients.

The impact of impairments on activities is considered an important rehabilitation outcome and has been studied extensively.[29-32] In contrast, little is known about stroke survivors' social participation and its determinants, particularly in Africa. A qualitative study completed in Rwanda involving 10 stroke patients found that inability to return to previous occupation, decreased social interactions, and inability to participate in religious activities were themes expressed when describing participation restrictions.[33] Another study carried out in Nigeria found that the level of disability and poststroke duration were associated to return to work poststroke.[34] A recent study conducted in Benin found that social participation evolves differently within sex, age, and severity of disability without causal pathway between the 3 factors.[19] Using the International Classification of Functioning, Disability and Health framework from the World Health Organization,[35] the present study aimed to build a model of prediction of social participation of community-dwelling stroke survivors in Benin at 1 month, 3 months, and 6 months.

Methods

Study design, setting, and ethical considerations

This study was a 6-month observational cohort study including 3 evaluation time points: 1 month, 3 months, and 6 months poststroke. The study was carried out in 3 outpatient rehabilitation centers in Benin from November 2015 to April 2016. The study was approved by the ethics committee of the Catholic University of Louvain (Belgium) and local ethics committees in Benin.

Inclusion criteria

Participants were eligible for inclusion if they met the following criteria: (1) clinical diagnosis of unilateral hemiplegia and/or paresis subsequent to a stroke experienced within 30 days, (2) no higher mental impairment and communication disorder that could prevent responding to questions in a face-to-face interview (Community Screening Instrument for Dementia[36] score $\geq$7), (3) 18 years or older, and (4) residence in a community (at home). Selected participants signed a consent form.

List of abbreviations:

6MWT	6-minute-walk test
ADL	activities of daily living
HADS	Hospital Anxiety and Depression Scale
PM-Scale	Participation Measurement Scale
PSD	poststroke depression
SIAS	Stroke Impairment Assessment Set

Variables

Independent variables

The Stroke Impairment Assessment Set (SIAS), which evaluates spasticity, aphasia, and motor impairments of the limbs, was used to assess impairments. All 22 SIAS items were rated from 0 (severely impaired) to 3 (normal), except the limb motor function items, which were rated from 0 (severely impaired) to 5 (normal). The SIAS total scores, which were the sum of the individual item scores, ranged from 0 (severely impaired) to 76 (normal).[37] The SIAS is a useful measure of stroke impairment with well-established and good psychometric properties.[10]

Depression was measured with the Hospital Anxiety and Depression Scale (HADS),[11] an assessment tool developed to detect states of depression and anxiety. In this study, only the depression subscale was used to screen for mood disorders. A higher HADS score represents a more depressive state; scores $>$10 usually indicate a mood disorder.[38]

Activity limitations were measured with the 20-item ACTIVLIM-Stroke scale,[12] which measures the "overall independence in activities of daily living" in adults with stroke. This instrument was validated previously by a Rasch analysis in a sample of stroke patients from Benin and Belgium and presents very good psychometric qualities with respect to validity, unidimensionality, reliability, linearity, and invariance.[12] Total ACTIVLIM-Stroke raw scores were subjected to logit and centile metric transformation to facilitate interpretation of the results; the centile data were analyzed. Higher measures indicate lower difficulty in activity of daily living. Walking ability was measured with the 6-minute walk test (6MWT).[13,39]

The severity of disability was categorized using the modified Rankin Scale,[40] which is one of the most widely used clinician-reported tool. Participants were rated from 0 (no symptoms at all) to 6 (dead). High modified Rankin Scale scores indicate worsening status.

Dependent variable

Participation was evaluated with the PM-Scale,[15,19] which was validated by a Rasch analysis in a sample of stroke patients from Benin and Burundi and presents very good internal consistency (person separation index = 0.93), test retest reliability (r>0.96), responsiveness (0.56$\leq$ effect size $\leq$2.13), and invariance. The PM-Scale consists of 22 items referring to daily situations encountered by stroke survivors in Africa. The scale was administered by way of face-to-face interviews. Participants were asked to provide their perceived participation on a 3-level scale: not at all (score = 0), weakly (score = 1), or strongly (score = 2). The "not at all" category corresponds to situations in which patients did not participate because of lack of motivation or capability (the 2 main personal factors that may determine an absence of participation). The "weakly" category corresponds to situations in which patients do not participate fairly often. The "strongly" category corresponds to situations in which patients participated actively and as often as possible. In addition, the

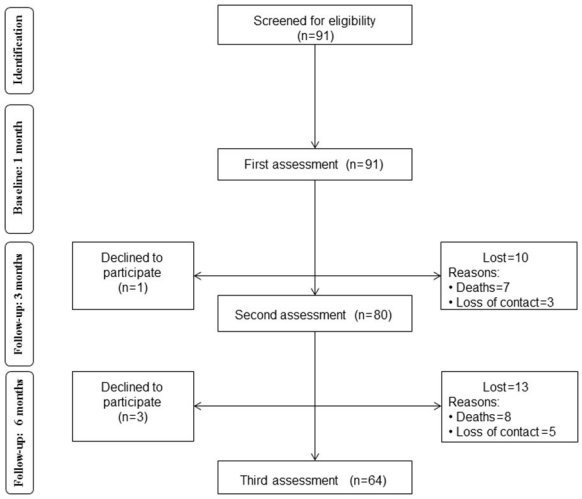

Fig 1 Flow chart of the enrollment in the study. Of the 91 eligible subjects, 64 participated in all 3 evaluations.

PM-Scale allows ordinal raw scores to be converted into interval-level measures in logits and in centiles. The total raw score of the PM-Scale ranges from 0 to 44 while the range of the linear measure in logit ranges from −6.56 to 6.51 logit, which corresponds to 0 to 100 centile. The linear measures in centiles were used in the present study. Higher measures indicate a higher participation.

Data collection

Potential participants were contacted by phone, and they were invited to participate in the study. During the 6 months of follow-up, each participant was evaluated at 3 time points: 1 month poststroke (T0), 3 months poststroke (T1), and 6 months poststroke (T2) by the same investigator (OK). In addition to the collection of demographic and clinical data, patients' assessment included the administration of the SIAS, the HADS, the ACTIVLIM-Stroke, the 6MWT, and the PM-Scale.

Sampling

The sample size needed for the present study was computed by considering an α error of 0.05 and an SD of 0.35 (equal to 35% in the centile measure) on the PM-Scale (which represents a conservative figure based on the SD value of 0.20 [equal to 20%] that was found in the validation study of the PM-Scale).[15] We also considered a minimal difference detection of 0.15 (15%) (based on the estimation of the location of the less difficult item of the PM-Scale as determined in the calibration study of the scale) and a power of 0.90. The minimal number of participants was 60. A systematic recruitment was done to include all patients fulfilling the inclusion criteria.

Statistical analyses

Descriptive statistics were used to summarize the study cohort's characteristics and to describe their participation levels at T0, T1, and T2. Correlations with participation as measured by the PM-Scale were determined with Spearman correlation coefficients for dichotomous and ordinal variables (sex, HADS scores, SIAS scores) or with Pearson correlation coefficients for continuous and interval variables (age, 6MWT, ACTIVLIM-Stroke measures, and PM-Scale). Variables that correlated significantly with participation (conservative significance threshold of 0.2) were included in a multiple forward stepwise linear regression[41] to build the best predictive equation of participation at each assessment time point. An adjusted coefficient of determination, which considers the number of selected variables, was used to avoid overestimating the predictive variance of the regression equation. Interactions between variables were examined by testing the significance of the model and individual variables without each interaction and after adding it. Possible confounders (sex, age, severity of disability) were examined by computing the index of relative variation of the model. The association of each variable with participation was tested for inclusion in the model using a significance level that is higher than the one set to define a cofactor.[42] This is usually set at $P<.2$ for univariate analysis and then set at $P<.05$ (or 95% CI) for retaining a factor in the final model.[41] Statistical analyses were performed in R software (R i386 3.5.2).[a]

Results

Figure 1 reports numbers of individuals considered for analyses at each assessment time point. Sixty-four individuals, including 45 men (70%) and 19 women (30%), with a mean age of 57±13 years were assessed 3 times over the full 6-month study period (table 1). The mean time since stroke at T0 was 24±6 days; 30 (52%) and 34 (41 %) participants had left paresis and right paresis, respectively. At T0, 50% of participants had a Rankin score ≥4, corresponding to moderately severe disability (unable to walk without assistance and unable to attend to own bodily needs without assistance). Some subjects were receiving outpatient rehabilitation but not specifically targeting the participation. None were receiving community rehabilitation. In addition, table 1 shows that the baseline values were similar ($P>.5$) between survivors ("full follow-up"), dropout, and deaths. Table 2 provides the descriptive statistics at each time point for all the variables included in the study. Participants showed a gradual improvement of their performance over time. In addition, the PM-Scale measures for our study sample at the T0 (1 month), T1 (3 months), and T2 (6 months) assessments are reported in figure 2A. Figure 2 also depicts the PM-Scale threshold map and items' description (Fig 2B) and an illustration of the relationship between the ordinal raw scores and the corresponding linear measures in logits and centiles (Fig 2C). We observed a progressive improvement in participation levels from T0 to T1 ($t=-2.02$; $P=.04$) and from T1 to T2 ($t=-3.04$; $P=.02$). Supplemental figure S1 (available online only at http://www.archives-pmr.org/) is provided for more details on the scoring proportion of each item of the PM-Scale.

Figure 3 depicts the correlation between the dependent variable (social participation, PM-Scale) for all the independent variables considered for the univariate analysis. Participation distribution skewed slightly higher, but not significantly so, in men than women at the 3 assessment time points ($0.07\leq\rho\leq0.2$; $P>.05$). Age significantly correlated with participation at T1 and T2, with younger patients participating more than older ones ($-0.14\leq r\leq-0.29$; $P<.05$). Depression (HADS) also correlated negatively with participation ($-0.71\leq\rho\leq-0.36$; $P<.05$). Conversely, impairments (SIAS score) ($0.46\leq\rho\leq0.78$; $P<.001$), walking performance (6MWT) ($0.56\leq r\leq0.71$; $P<.001$), and performance in

Table 1 Comparison of baseline values

Variable	Full Follow-up (N=64)	Deaths (n=15)	Dropout (n=12)	*P* Value*
PM-Scale, %, mean ± SD	41±12	40±9	42±10	.61*
ACTIVLIM-Stroke, %, mean ± SD	39±15	38±5	38±9	.14*
Age (y), mean ± SD	57±13	59±15	57±17	.74*
Time since stroke (d), mean ± SD	24±6	19±8	20±10	.63*
HADS, median [P25; P75]	10 [7-14]	12 [9-12]	11 [9-13]	.07†
SIAS, median [P25; P75]	28 [18; 34]	26 [17; 31]	25 [16; 32]	.52†
mRS score, median [P25; P75]	4 [3; 4]	4 [3; 4]	3 [3; 4]	.65†
Sex				
Male, n (%)	45 (70)	9 (60)	8 (33)	.89‡
Female, n (%)	19 (30)	6 (40)	4 (67)	

Abbreviations: mRS, modified Rankin Scale.
* Analysis of variance.
† Mann-Whitney test.
‡ χ^2 test.

activities of daily living (ADL) (ACTIVLIM-Stroke) ($0.63 \leq r \leq 0.82$; $P < .001$) correlated positively with participation. Among the examined variables, ADL (ACTIVLIM-Stroke) had the strongest correlation with participation.

Table 3 reports the final regression model and associated statistics at each time point and for each determinant of participation. The linear regressions of the analyzed predictors in total accounted for an adjusted coefficient of determination of social participation of 0.44 at T0, 0.65 at T1, and 0.78 at T2. As shown in table 3, the regression model at the 3 time points suggests that ADL (ACTIVLIM-Stroke) were the strongest predictor of participation within the first 6 months poststroke; depression (HADS) was the second significant predictor at T0, and T1 and was the third significant predictor at T2. Impairments were the second significant predictor at T2.

Discussion

The purpose of this study was to build a model of prediction of social participation during the acute to postacute phases of stroke recovery at 1 month (T0), 3 months (T1), and 6 months (T2) in Benin. The results showed that ADL performance (ACTIVLIM-Stroke) and depression (HADS) were the significant predictors of social participation (PM-Scale) at T0 and T1. At T2, ADL, impairments (SIAS), and depression (HADS) were the significant predictors.

Our findings indicated that at 1 month, activity limitations and depressive symptoms are important predictors of social participation poststroke in Benin. This provides useful information for poststroke care in Benin given that little is known about the evolution of participation following hospital discharge. Short-term improvement in patient functioning is critical because this acute period is when patients are in contact with the health care system and can still benefit substantially from a rehabilitation program promoting long-term recovery. In a 6-month follow up study, Hamzat and Peters investigated motor function and participation among Nigerian stroke survivors, who share a medico-sociocultural environment comparable with Benin after hospital discharge.[43] A significant correlation was observed between total scores of the Modified Motor Assessment Scale (a mixed impairment and activity scale) and the London Handicap Scale score (participation measure) at the first month. A previous study also found that despite similar severity of stroke on admission to a rehabilitation unit, poststroke depression (PSD) patients showed greater disability in coping with ADL (evaluated by means of Barthel Index) and greater participation restrictions than post-stroke patients with no depression.[42] While supporting these previous findings, this study shows that recovery of ADL and PSD should be more emphasized in early rehabilitation programs poststroke in Benin, since they are the most important predictors of social participation in the acute and postacute stages of recovery.

By the 3-month assessment, the mean participation level (PM-scale) for our study sample had increased to 45%, with activity limitations and depression remaining the most important determinants of participation. The 3-month time point is a stroke recovery milestone[4,27,32] because it is considered the end of the

Table 2 Descriptive statistics on participation and its determinants

Variables	T0 (n=91) Mean ± SD	T1 (n=80) Mean ± SD	T2 (N=64) Mean ± SD	T0 vs T1 *P* Value	T1 vs T2 *P* Value
PM-Scale measures (%)	41±12	45±12	53±15	.04	.02
ACTIVLIM-Stroke measures (%)	38±17	47±15	55±16	.001	.002
6MWT measures (m)	109±161	178±195	261±235	.013	.031
HADS scores	11 [8-13]*	9 [6-11]*	7 [5-9]*	.007†	.03†
SIAS scores	29 [23-36]*	34 [30-40]*	39 [35-44]*	<.001†	<.001†

* Median [P25-P75].
† Mann-Whitney test.

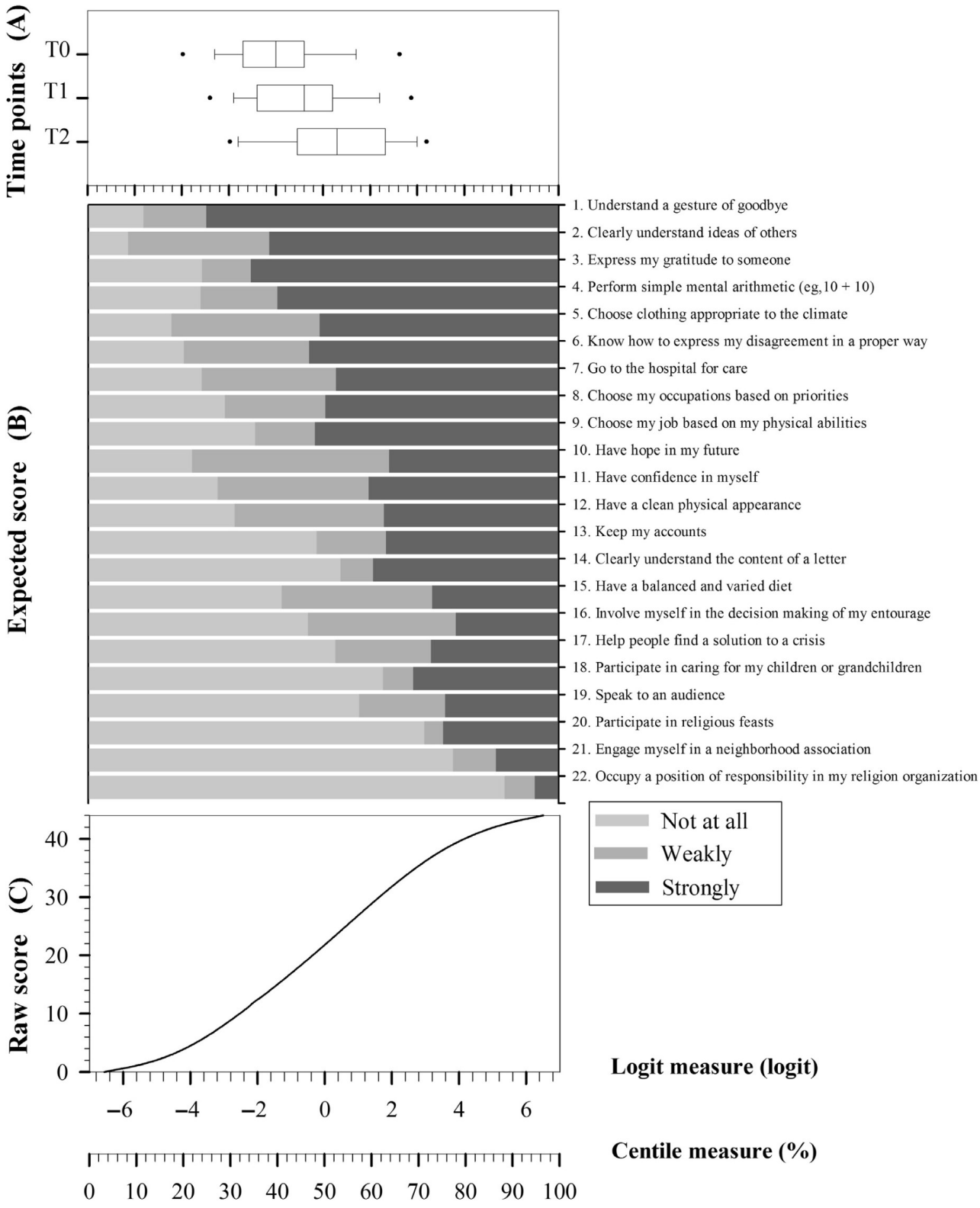

Fig 2 Sample's participation. The top panel (A) shows the distribution of the subjects' participation measures at 1 month (T0), 3 months (T1), and 6 months (T2) poststroke. Each box shows the median and interquartile range of the participation measures distribution. The whisker lengths represent 1.5 times the interquartile range above the upper quartile and below the lower quartile. Values beyond these are plotted as outliers. The middle panel (B) shows the threshold map of the PM-Scale indicating the expected response for each item as a function of subjects' participation level. The bottom panel (C) shows the relationship between the ordinal raw scores and the corresponding linear measures in logits and in centiles (%).

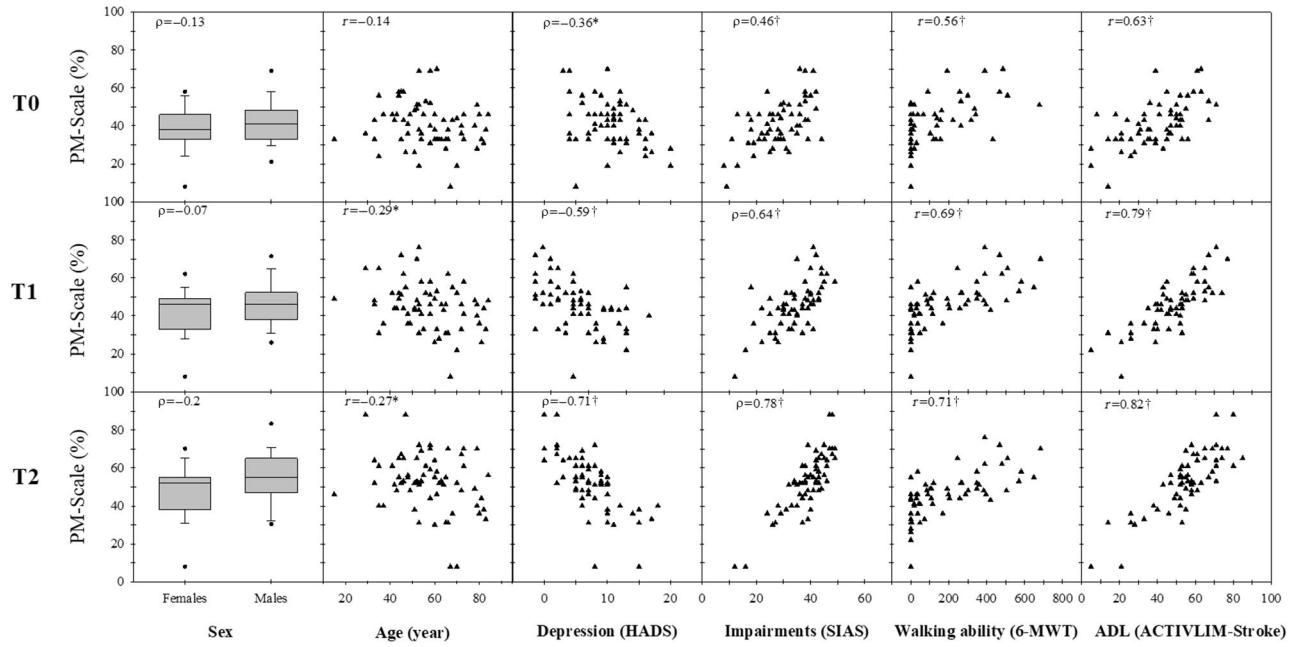

Fig 3 Relationships between participation and sex, age, depression (HADS), impairments (SIAS), walking performance (6MWT), and performance in ADL (ACTIVLIM-Stroke). For each variable, Pearson (r) or Spearman (ρ) correlation coefficient was calculated as appropriate. Significant correlations were indicated with the symbol * ($P<.05$) or † ($P<.001$).

acute care period and thus marks the patient's transition to resuming usual ADL. Previous studies also found that physical abilities at this time point, including walking endurance, balance, lower extremity motor coordination, and upper extremity function, were good predictors of participation of people recovering from a stroke.[19,28,44] Hemiparesis, a common poststroke condition, can limit activity because of impaired gait, which in turn can reduce perceived social participation.[44] Although a majority of stroke survivors are able to walk independently 6 months poststroke,[44,45] at 3 months many require walking aids, cannot walk with sufficient speed, and are restricted in their indoor and outdoor mobility.[45-47]

At the 6-month assessment, we found that the most important determinants of participation were activity limitations, overall impairment level, and depression. In a recent study of stroke patients conducted in Brazil, Silva et al[48] found that the Functional Independence Measure (ADL measure) was the main predictor of social participation and that the presence of depressive symptoms was a moderate predictor. Our findings support those of that study since the ACTIVLIM-Stroke scale used in the present study is also a measure of functional independence in ADL. In Uganda, PSD was found to be strongly associated with the ADL (Barthel index).[49] In Ghana, another study found that PSD correlated with the physical, psychosocial, cognitive, and ecosocial domains of quality of life.[50] In addition, in our study the correlation matrix at 6 months also highlights a relationship between participation and motor function. This result is also supported by a previous study on life habits, where an observed association between motor function and participation suggested that as patients were regaining motor function, their participation level was also improving.[43]

To our knowledge, this is the first study investigating determinants of social participation poststroke in West Africa by

Table 3 Regression results at each time point

	T0 (n=91)		T1 (n=80)		T2 (N=64)	
Variables	β	95% CI	β	95% CI	β	95% CI
ACTIVLIM-Stroke measures (%)	0.4	[0.3 to 0.6]*	0.58	[0.4 to 0.7]*	0.31	[0.2 to 0.5]*
HADS scores	−0.6	[−0.8 to −0.2]*	−0.58	[−0.5 to −0.7]*	−0.94	[−0.8 to −0.2]*
SIAS scores	NA	NA	NA	NA	0.82	[0.8 to 0.9]
Final model Equation	31.8+0.4.ACTIVLIM-Stroke −0.6.HADS	NA	22.3+0.58.ACTIVLIM-Stroke−0.58.HADS	NA	31.8+0.31.ACTIVLIM-Stroke+0.82.SIAS−0.94.HADS	NA
R^2	0.44	NA	0.65	NA	0.78	NA

Abbreviation: NA, not applicable.
* Significant.

instruments that are socioculturally tailored to the context with very good psychometric properties, namely ACTIVLIM-Stroke and PM-Scale. In our sample, a strongest relation was observed at 6 months between social participation as measured by the PM-Scale and its underlying determinants (ADL, depression, impairments). The study findings are important in the improvement of rehabilitation programs and in the (continuing) training of rehabilitation professionals since it highlights the determinants that are modifiable by interventions at different time points in poststroke rehabilitation.

Study limitations

The present study was limited by our inability to generalize the findings to patients with aphasia or major cognitive impairments because such patients were excluded from the study cohort. In addition, future studies could use more robust analyses than stepwise regression, such as the structural equation modeling for the determination of causal dependencies between social participation-selected independent variables.

Conclusions

The present study identified factors that determine social participation poststroke in Benin using socioculturally tailored tools. The study results suggest that ADL (ACTVLIM-Stroke), depression (HADS), and overall impairments (SIAS) were the significant predictors of social participation during the 6 months following a stroke. These findings will be a valuable resource for stakeholders interested in evaluating interventions, programs, and policies designed to assess and encourage rehabilitation for stroke patients in Benin. Nonetheless, further studies are required to take into account patients with severe cognitive impairments and aphasia.

Supplier

a. R software (R i386 3.5.2); R Foundation for Statistical Computing.

Keywords

Rehabilitation; Stroke

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