"Tracking Changes in Participation With Participation Measurement Scale in Community-Dwelling Stroke Survivors in Africa"

Kossi, Oyene ; Thonnard, Jean-Louis

ABSTRACT

OBJECTIVE: To investigate responsiveness of the Participation Measurement Scale (PM-Scale) for the measurement of participation of stroke survivors. DESIGN: A 6-month observational study with 3 evaluation time points. Responsiveness of the PM-Scale was investigated over a period of 6 months. SETTING: Rehabilitation centers. PARTICIPANTS: Stroke survivors (N=64); mean age ± SD, 56.9±12.6 years; sex, 45 men (70%). INTERVENTIONS: Not applicable. MAIN OUTCOME MEASURES: Participants were evaluated using the PM-Scale. The modified Rankin Scale was used to categorize the overall disability level for each participant. RESULTS: The mixed-effect model analysis showed a significant difference in the participation over time (χ²=35.04; df=2; P<.001). In addition, the model exhibited significant effects of the sex, age, and disability at enrollment on the subjects' participation levels. Furthermore, the PM-Scale detected different levels of changes in the entire cohort over time (small change, effect size [ES]=0.33; moderate change, ES=0.67; and large change, ES=1). The PM-Scale also facilitated the classification of the participants into discriminative categories such as important improvement (t score≥1.96; 1.8≤ES≤2.13), moderate improvement (0<t score<1.96; 0.56≤ES≤0.78), no change (t score=0), moderate decrease (-1.96<t score<0; ES=0.67), and important decrease (t score≤-1.96; ES=1.47). CONCLUSIONS: The PM-Scale exhibited good responsiveness and accurately detected changes in stroke subjects' involvement in life situations. These results validate the usefulness...

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Tracking Changes in Participation With Participation Measurement Scale in Community-Dwelling Stroke Survivors in Africa

Oyéné Kossi, PhD,a,b Jean-Louis Thonnard, PhD,a,c

Abstract

Objective: To investigate responsiveness of the Participation Measurement Scale (PM-Scale) for the measurement of participation of stroke survivors.

Design: A 6-month observational study with 3 evaluation time points. Responsiveness of the PM-Scale was investigated over a period of 6 months.

Setting: Rehabilitation centers.

Participants: Stroke survivors (N = 64); mean age ± SD, 56.9 ± 12.6 years; sex, 45 men (70%).

Interventions: Not applicable.

Main Outcome Measures: Participants were evaluated using the PM-Scale. The modified Rankin Scale was used to categorize the overall disability level for each participant.

Results: The mixed-effect model analysis showed a significant difference in the participation over time ($\chi^2 = 35.04; df = 2; P < 0.001$). In addition, the model exhibited significant effects of the sex, age, and disability at enrollment on the subjects’ participation levels. Furthermore, the PM-Scale detected different levels of changes in the entire cohort over time (small change, effect size [ES] = 0.33; moderate change, ES = 0.67; and large change, ES = 1). The PM-Scale also facilitated the classification of the participants into discriminative categories such as important improvement ($t$ score $\geq 1.96$; 1.8$<t$ score$\leq 2.13$), moderate improvement ($0 < t$ score$< 1.96$; 0.56$<t$ score$\leq 0.78$), no change ($t$ score$= 0$), moderate decrease ($-1.96 < t$ score$< 0$; ES = 0.67), and important decrease ($t$ score$\leq -1.96$; ES = 1.47).

Conclusions: The PM-Scale exhibited good responsiveness and accurately detected changes in stroke subjects’ involvement in life situations. These results validate the usefulness of the PM-Scale for clinical trials and in settings to evaluate the effects of interventions on subjects with stroke in Africa.

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Stroke is a common cause of death and a leading cause of severe long-term disability in both developed and developing countries.1,2 In Africa, the prevalence of stroke is among the highest worldwide.3 Individuals who survive a stroke often have to cope not only with impaired body functions and structures, but also with activity limitations and participation restrictions. In Africa, the 1-year mortality rate after stroke has been estimated to be 20%.2,4 Almost 20 years ago, the International Classification of Functioning, Disability and Health5 was published, and it defined participation as an individual’s involvement in life situations. Since then the topic continues to be a subject of interest in health care, social, and rehabilitation sciences. Participation is particularly relevant because it goes beyond physical impairments and disabilities, and considers the influences of contextual factors that can affect an individual in his or her own environment.6

Acquiring accurate information regarding participation after stroke is essential because it can serve as a baseline for health care planning.2,7,8 It can also facilitate the establishment of therapeutic...
guidelines and social interventions. As with any latent variable, assessment of participation requires the use of individual-reported outcome measures. The Participation Measurement Scale (PM-Scale) is an interview-based scale with 22 items which has recently been proposed to measure participation after stroke in the African context. The 22 items of the PM-Scale cover the 9 domains of participation, as described in the International Classification of Functioning, Disability and Health. In addition to being a disease-specific scale, the PM-Scale presents very good psychometric properties, including validity, reliability, unidimensionality, and invariance, and is very easy to administer. The 22 items of the PM-Scale describe common situations for community-dwelling stroke survivors in Africa, provide an equal basis for monitoring social participation after stroke, and may be very useful in multicenter studies. However, the responsiveness of the PM-Scale has not been investigated. Responsiveness reflects the ability of a scale to detect changes over time, and this is an important psychometric quality and an essential criterion for instrument selection when measuring patient functioning in chronic diseases (O. Kossi, unpublished data, 2017). Previous studies have suggested that several factors contribute to participation restrictions after stroke, including cognitive deficits, emotional deficits, functional dependency, and increasing age. However, little is known about the evolution of participation during the months after the stroke in the African context. Therefore, this study aimed to investigate the responsiveness of the PM-Scale over a period of 6 months and to test whether sex, age, and disability at enrollment have effects on participation in a cohort of stroke subjects.

Methods

Ethical considerations and inclusion criteria

This 6-month observational cohort study was approved by the local ethics committees. Participants were recruited from patients’ registers of 3 rehabilitation centers. Subjects were eligible for inclusion if they met the following criteria: (1) unilateral hemiplegia/paresis subsequent to a stroke was experienced within 30 days; (2) absence of major cognitive impairments that could prevent the subject from responding in a face-to-face interview (Community Screening Instrument for Dementia score \( \geq 7 \)); (3) age \( \geq 18 \) years; and (4) living in a community (at home). All participants signified their agreement to participate by signing a consent form.

Procedure and instruments

During the follow-up process, each participant was evaluated at 3 time points: at enrollment (T0), 3 months poststroke (T1), and 6 months poststroke (T2). Subjects’ participation levels were assessed with the PM-Scale, which consists of 22 items that refer to daily situations encountered by stroke survivors in Africa (eg, “Participate in religious feasts,” “Engage myself in a neighborhood association,” “Occupy a position of responsibility in my church organization,” and so on). The PM-Scale was administered by face-to-face interviews in French language. Participants were asked to report their perceived participation level for each situation on a 3-category scale labeled as: “not at all” (score = 0), “weakly” (score = 1), or “strongly” (score = 2). As described in the validation study, all the 22 items fitted a single dimension (mean fit residual: -0.04±1.2). The hierarchy of item difficulty was also invariant across the scale \( (\chi^2 = 80.6; P = .11) \) and the PM-Scale showed good internal consistency (person separation index: 0.93). The scale also presented excellent reproducibility within 2 weeks \( (r > 0.96, P <.001) \) and allows ordinal raw scores to be converted into interval-level measures (in logit and in centiles). The centiles metric transformation was applied to the PM-Scale raw scores because this is a more common transformation. Higher scores indicate higher participation levels.

The modified Rankin Scale (mRS), which is one of the most widely used clinician-reported tools, was employed to categorize overall disability for each participant. The mRS was administered by a physical therapist working with stroke patients for >10 years. Participants were rated from 0 (“no symptoms at all”) to 6 (“dead”). High mRS scores indicate worsening status.

Sample size and participants

To determine the sample size needed for the present study, an error of 0.05, an SD of 0.35 on the PM-Scale (which represents a conservative figure based on the SD value of 0.20 that was found in the validation study of the PM-Scale), a minimal difference detection of 0.15, and a power of 0.90 were considered. Thus, 60 participants were determined to be the required sample size. A total of 91 eligible participants agreed to participate and were enrolled in the study. During the follow-up process, 12 subjects dropped out and 15 deaths were reported (fig 1). These data were considered as missing values. Baseline values on the assessment tools (PM-Scale and mRS) were similar \( (P >.5) \) among survivors, subjects dropped out, and deaths.

Data analysis

Descriptive statistics were used to present the characteristics of the study sample. A linear mixed-effect model analysis for repeated measurements within participants was used to investigate the effects of sex, age, and disability at enrollment on the subjects’ participation levels over time. Analyses were performed using R software under a longitudinal random intercept-slope model. Sex, age, and disability status at enrollment were entered into the model as fixed effects. Random intercepts per individual were considered, as well as random slopes per individual for the effect of time. Interactions between sex, age, disability at enrollment, and time since stroke were investigated. The \( P \) values were obtained by likelihood ratio tests of the full model with the effect in question against the model without the effect.

Effect size (ES) was used to characterize the magnitude of the internal responsiveness to change in the PM-Scale. ES was calculated based on the mean change between the average measures of 2 evaluations divided by the SD of the first evaluation. ES data were then interpreted by using Cohen’s benchmarks, with the magnitude of the changes classified as nonsignificant \( \text{(ES}< 0.2) \), small \( (0.2 \leq \text{ES} < 0.5) \), moderate \( (0.5 \leq \text{ES} < 0.8) \), or large \( \text{(ES} \geq 0.8) \).

First, ES was investigated at the entire sample level. Second, to accommodate the consideration that changes that occur in a group

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**List of abbreviations:**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ES</td>
<td>Effect size</td>
</tr>
<tr>
<td>mRS</td>
<td>Modified Rankin Scale</td>
</tr>
<tr>
<td>PM-Scale</td>
<td>Participation Measurement Scale</td>
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</tbody>
</table>
may not be meaningful to individuals, \textsuperscript{21} changes in participation were evaluated at the individual level. For this, \( t \) values, which take into account self-relative scores and their associated errors for a person at 2 different time points, were calculated as follows: \textsuperscript{22}

\[
t \text{value} = \frac{(p_i - p_j)}{\sqrt{(SE_j^2 + SE_i^2)}}
\]

where \( p_i \) and \( p_j \) represent the subject’s participation level at 2 time points, and \( SE_j \) and \( SE_i \) are the respective associated standard errors of measurement. Calculation of \( t \) values follows a standardized normal distribution and indicates whether the changes observed between 2 assessment times for a given subject reflect more than a fluctuation of the measuring instrument. \textsuperscript{23} The participants were divided into 5 classes according to their \( t \) score significance limits: important improvement \((t \geq 1.96)\), improvement \((0 < t < 1.96)\), no change \((t = 0)\), deterioration \((-1.96 < t < 0)\), and important deterioration \((t \leq -1.96)\).

**Results**

**Sample’s characteristics**

A total of 64 participants (45 males, 19 females), mean age \( \pm \) SD, 56.9\( \pm \)12.6 years and time since stroke \( \pm \) SD, 24.2\( \pm \)6.1 days, underwent the 3 evaluations. The sample’s characteristics are presented in table 1.

**Global evaluations**

The mixed-effect model analysis showed a significant difference in participation over time \( (\chi^2 = 35.04; df = 2; P < 0.001) \). In
addition, the model showed significant effects of sex (the males participated more than the females), age (younger subjects participated more than older subjects), and disability at enrollment (high mRS scores implied less participation levels).

The evolution of the sample’s participation over time is presented in fig 2 and in table 2. Figure 2 highlights a gradual improvement of the participation levels of the sample from T0 to T2. Calculations of ES (see table 2) showed that the entire cohort exhibited a small change between enrollment and 3 months (ES = 0.33), moderate change between 3 and 6 months (ES = 0.67), and large change between enrollment and 6 months (ES = 1).

Individual evaluation
At the individual level, 36 participants (56.3%) exhibited improvement or important improvement in the PM-Scale measures between T0 and T1, whereas 23 participants (36%) decreased or importantly decreased at the same time (table 3). Between T1 and T2, 47 participants (73.4%) showed improvement or important improvement, whereas 9 participants (14%) decreased or importantly decreased (see table 3).

Discussion
This study examined the ability of the PM-Scale to detect changes over time in a sample of stroke survivors. Participants were followed for 6 months without any specific intervention targeting their participation. Responsiveness of the PM-Scale was evaluated at global, group, and individual levels. The results show that the PM-Scale is sensitive to change and can accurately detect even minor but relevant changes in participants over time.

When a global approach was used to analyze the PM-Scale data (see table 2), it was observed that participation levels significantly increased from 41% to 45% between T0 and T1, and from 45% to 53% between T1 and T2. These changes were respectively confirmed by small and moderate ES values. However, use of a global approach has the potential to mask important information because data are pooled and distinctions are not made between groups and individuals. For this reason, we also performed factor-based and individual-based analyses which revealed further details of the present data.

Results of the mixed-effect analysis showed that sex had a significant effect on the subjects’ participation levels over the 6 months of follow-up. However, further analyses suggested that the age and severity of disability in males did not significantly differ from those of females. In Nigeria, Vincent-Onabajo et al. also found that participation levels differ between males and females, although not significantly. In their study, the males had slightly higher median scores with the London Handicap Scale than females between 1 and 9 months of follow-up. Causes of poorer functioning after stroke in women than in men are not well known. Previous studies have suggested that marital status may contribute to worse functioning after stroke in women. In particular, being widowed has been associated with poorer outcome, and this may be due to the negative effect of increased social isolation as a widow. However, in African communities, older women are dutifully cared for by family members, especially their children, as a show of appreciation for the care they received in early life. It has also been hypothesized that preexisting limitations may impact poststroke outcome. In the present study, the lower improvement in participation level in the females compared to the males may be attributed to sociocultural factors that hinder the involvement of women in life situations. For example, on a routine basis, males are more stimulated and have more opportunities to participate in social and community activities, such as leisure, playing on a team, being involved in a neighborhood association, and/or occupying a position of responsibility in most African communities, than females. This suggests that in African communities, improvement of female stroke patients’ participation could require an upstream action whereby healthy women are given opportunities to be more engaged in community, social, and civic life activities.

Age is one of the critical risk factors of stroke. In general, older patients present with more severe poststroke neurological and behavioral deficits than younger patients. However, Desrosiers et al. have suggested that reduced participation after stroke may partly be attributed to normal aging and not entirely to the stroke itself. They observed that in healthy community-dwelling people aged 55 years and older, social participation significantly decreased with advancing age. In the present study, younger subjects consistently showed more improvement in their participation levels than older subjects. As observed in our study and in several previous studies, stroke occurs earlier in African communities than in occidental communities. Consequently, cost-effective and suitable programs for younger individuals could considerably boost participation after stroke in community-dwelling survivors in Africa.
In this study, the whole sample exhibited improved participation over time. However, consistent with the individual approach used in previous studies, we observed that individuals in a group do not equally experience the mean change of the group, and valuable insights regarding responsiveness can be obtained with analyses at an individual level. The opportunity to interpret results at the individual level is very important in clinical settings where each patient is his or her own control over time. Furthermore, individual analyses are possible because the PM-Scale allows raw scores to be converted into linear measures with associated standard errors of the measurement. Evaluations of individual participation levels also provided the opportunity to add classification categories such as important improvement, improvement, no change, decrease, and important decrease. As shown in tables 2 and 3, our data clearly indicate that the PM-Scale can measure different magnitudes of change over time in the stroke survivors’ participation.

Instruments that are responsive to severe or mild disabilities are required for the clinical follow-up of patients. Indeed, because of the ceiling effect, some scales are not very useful in clinical trials that enroll subjects with severe disease conditions. In the present study, high sensitivity to changes in participation was observed in patients with minor to moderate disability, as well as in those with severe disability, thereby confirming the usefulness of the PM-Scale for clinical practice and research settings.

### Study limitations

The present study investigated the ability of the PM-Scale to detect changes over time on the basis of a sample of stroke survivors from the Benin Republic. Further studies should test the responsiveness of this first Africa-specific tool for the measurement of participation in other African countries.

### Conclusions

Tracking changes in participation of patients with chronic diseases is an important consideration in rehabilitation care. In the present study, different statistical indices and methodological approaches were combined to investigate the responsiveness of the PM-Scale, a simple questionnaire that focuses on participation after stroke in the African context. Our results show that the PM-Scale is responsive and can be used to track changes that occur in stroke subjects. In addition, the PM-Scale can be used to evaluate the effects of clinical interventions and to guide various stages of health service provision, including assessment, goal setting, and program planning, for individuals and groups in Africa.

### Suppliers

- a. R software; Core Team R.
- b. lme4 package; R package version 0.999999-0.

### Keywords

- Rehabilitation
- Stroke

### Corresponding author

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### Table 2

<table>
<thead>
<tr>
<th>Type of analysis</th>
<th>T0 Mean ± SD (%)</th>
<th>T1 Mean ± SD (%)</th>
<th>T2 Mean ± SD (%)</th>
<th>ES T0 vs T1</th>
<th>T1 vs T2</th>
<th>T0 vs T2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Global evaluation (n = 64)</td>
<td>41±12</td>
<td>45±12</td>
<td>53±15</td>
<td>0.33 *</td>
<td>0.67 y</td>
<td>1 z</td>
</tr>
</tbody>
</table>

NOTE. T0, at enrollment; T1, 3 months poststroke; T2, 6 months poststroke.

* Small change.
y Moderate change.
z Large change.

### Table 3

<table>
<thead>
<tr>
<th>t value category</th>
<th>n</th>
<th>T0 mean ± SD (%)</th>
<th>T1 mean ± SD (%)</th>
<th>ES</th>
<th>n</th>
<th>T1 mean ± SD (%)</th>
<th>T2 mean ± SD (%)</th>
<th>ES</th>
</tr>
</thead>
<tbody>
<tr>
<td>t ≥ 1.96</td>
<td></td>
<td>Important</td>
<td>19 35±8</td>
<td>53±10</td>
<td>2.13 *</td>
<td>21 44±10</td>
<td>62±12</td>
<td>1.8 *</td>
</tr>
<tr>
<td>0 &lt; t &lt; 1.96</td>
<td></td>
<td>Improvement</td>
<td>17 39±13</td>
<td>46±13</td>
<td>0.56</td>
<td>26 47±8</td>
<td>53±9</td>
<td>0.781</td>
</tr>
<tr>
<td>t = 0</td>
<td></td>
<td>No change</td>
<td>5 32±14</td>
<td>32±14</td>
<td>NA</td>
<td>8 33± 2</td>
<td>33±12</td>
<td>NA</td>
</tr>
<tr>
<td>−1.96 &lt; t &lt; 0</td>
<td></td>
<td>Decrease</td>
<td>19 47±9</td>
<td>41±9</td>
<td>0.67</td>
<td>8 55±19</td>
<td>49±21</td>
<td>0.32 z</td>
</tr>
<tr>
<td>t ≤ −1.96</td>
<td></td>
<td>Important decrease</td>
<td>4.55±11</td>
<td>39±12</td>
<td>1.45 *</td>
<td>1 NA</td>
<td>NA</td>
<td>NA</td>
</tr>
</tbody>
</table>

NOTE. T0, at enrollment; T1, 3 months poststroke; T2, 6 months poststroke.

* Large change.
1 Moderate change.
z Small change.
Acknowledgments

We thank all the participating subjects for their helpful involvement in this study. We are also grateful to Céline Bugli, PhD, and to Mickaël De Backer, PhD, from the Institute of Statistics, Biostatistics and Actuarial Sciences, Catholic University of Louvain, for their contribution to the statistics performed.

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