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ORIGINAL RESEARCH

Measuring Participation After Stroke in Africa: Development of the Participation Measurement Scale

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Abstract

Objective: To develop a valid stroke-specific tool, named the Participation Measurement Scale (PM-Scale), for the measurement of participation after stroke.

Design: Observational study and questionnaire development.

Setting: Outpatient rehabilitation centers.

Participants: Patients with stroke (N=276; mean age, 58.5±11.1y; 57% men).

Interventions: Not applicable.

Main Outcome Measures: Participants completed a 100-item experimental questionnaire of the PM-Scale. Items were scored as "not at all," "weakly," or "strongly." The Hospital Anxiety and Depression Scale was used to evaluate depression, and the modified Rankin Scale was used to categorize the severity of disability on the basis of observation.

Results: After successive Rasch analyses using unrestricted partial credit parameterization, a valid, unidimensional, and linear 22-item scale for the measurement of participation was constructed. All 22 items fulfilled the measurement requirements of overall and individual item and person fits, category discrimination, invariance, and local response independence. The PM-Scale showed good internal consistency (person separation index, .93). The test-retest reliability of item difficulty hierarchy ($r=.96$; $P<.001$) and patient location ($r=.99$; $P<.001$) were excellent. This patient-based scale covers all 9 International Classification of Functioning, Disability and Health domains of participation.

Conclusions: The PM-Scale has good psychometric qualities and provides accurate measures of participation in patients with stroke in Africa. Archives of Physical Medicine and Rehabilitation 2018;99:652-9

Stroke remains a major global health problem,[1-3] and its significance is likely to increase in the future because of ongoing demographic changes, including aging of the population and health transitions observed in developing countries.[2,4] In Africa, the estimated pooled prevalence rate of stroke is 3.5 cases per 1000 people, with an annual increase of 12.0%.[5] Disability after stroke results from complex and dynamic interactions between impairments and contextual barriers, which could hinder individuals' participation in society.[6] Participation has been described in the International Classification of Functioning, Disability and Health (ICF)[7] as an individual's involvement in life situations and is assessed using different domains: learning and applying knowledge; mental functions in general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; employment and economic life; and community, social, and civic life.

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Since the publication of the ICF in 2001, the concept of participation has become central in discussions across rehabilitation science.[8] Much has been written to describe and explore how to measure participation.[9-12] Several ICF-based tools have been designed, most notably in the occidental context, to assess participation in patients with stroke. These tools include the Community Integration Questionnaire,[13] SATIS-Stroke scale,[9] Reintegration to Normal Living Index,[10] London Handicap Scale,[14] Participation Enfranchisement Scale,[11] and World Health Organization Disability Assessment Schedule 2.0 in stroke.[15] A recent systematic review (O. Kossi, E.R. Amanzonwe, J.L. Thonnard, C.S. Batcho, unpublished data, 2017) examined the performance of existing ICF-based tools in measuring participation and quality of life in stroke survivors and found some limitations in their applicability to the African sociocultural context. These limitations concern the administration procedure, which is by mail, by post, or by self-report for some tools.[9,10] These administration procedures could be difficult to apply in some areas of Africa, namely, in Central and West Africa, where a small percentage of people have a postal address and a small proportion of adults (age, ≥55y) can read and write.[16] Other sociocultural differences across continents are, for example, the existence and use of public transportation as well as the religious beliefs. For instance, in Benin the most widespread type of transportation is the motorcycle taxi locally called "taxi moto." Moreover, in most African communities a large part of the population is religious, either through Christianity or Islam or through endogenous religions. Such differences between societies need to be taken into account when measuring latent variables such as participation. Consequently, culturally tailored measurement of participation in stroke survivors in Africa may require complete bottom-up redevelopment of a new scale. Content validity, category discrimination, and item invariance regarding context-specific factors of individuals should be evaluated with respect to the targeted population. Therefore, in this study we aimed to design and validate a new scale, named the Participation Measurement Scale (PM-Scale), for the measurement of participation after stroke in Africa.

Methods

Inclusion criteria and ethical considerations

We identified potential participants using the patient registers of 15 rehabilitation centers in Benin (West Africa) and Burundi (East Africa). Then, they were contacted by phone by the investigator and they were invited to participate in the study. To be enrolled, patients had to meet the following criteria: (1) presence of unilateral hemiplegia/paresis subsequent to a stroke that had occurred at least 2 weeks previously; (2) absence of any major cognitive impairment that could prevent response in a face-to-face interview (Community Screening Instrument for Dementia[17] score, ≥7); (3) age ≥18 years, and (4) living in a community (at home).

The study was approved by the Research Ethics Committee of Université catholique de Louvain (Belgium) and the local ethics committees in Benin and Burundi. All participants signified their agreement to participate by signing a consent form.

List of abbreviations:

DIF	**differential item functioning**
HADS	**Hospital Anxiety and Depression Scale**
ICF	**International Classification of Functioning, Disability and Health**
mRS	**modified Rankin Scale**
PM-Scale	**Participation Measurement Scale**
PSI	**person separation index**

Patient assessment

In addition to the collection of demographic and clinical data, patient assessment included administration of the experimental version of the PM-Scale, the modified Rankin Scale (mRS),[18] and the Hospital Anxiety and Depression Scale (HADS).[19] All participants were evaluated at the time of enrollment, and a subsample of 151 patients was evaluated a second time within 2 weeks by the same investigator to investigate the test-retest reliability of the PM-Scale.

Experimental version of the PM-Scale

Using the ICF framework and existing participation scales for patients with stroke,[9-11,13-15] we generated a preliminary list of 107 items related to participation, with 14 items specifically tailored to the African sociocultural context. The process followed to develop the initial 107 items of the PM-Scale was similar to the Qualitative Item Review Process.[20] The content validity of this preliminary list was checked by 3 medical doctors, 12 physical therapists, and 2 nurses involved for at least 3 years in stroke rehabilitation in Benin and Burundi. They were asked to identify items that were not relevant to patients with stroke, to suggest relevant items that were missing, and to review the reading/comprehension level of the questionnaire. No new item was proposed, but 7 items were identified as irrelevant and removed. This experimental version of the PM-Scale, composed of 100 items, was administered to our sample in face-to-face interviews. This choice was motivated by high variability in the reading ability of our participants, which precludes a self-report procedure. To target the participation dimension, patients were asked to indicate their perceived involvement in each situation on a 3-level scale scored as "not at all" (0), "weakly" (1), and "strongly" (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. For situations not encountered or attempted during the last 3 months, item data were recorded as missing. Study participants were interviewed in French language by 2 of the authors (O.K. in Benin and F.N. in Burundi). However, for publication purpose, the final 22 items were translated into English using a back/forward translation method.

The mRS and HADS

The mRS[18] is a generic ordinal clinician-rated tool that categorizes the severity of disability on the basis of observations. Patients are rated on 7 levels, ranging from 0 ("no symptom at all") to 6 ("dead"). Higher mRS scores indicate worse conditions. The HADS[19] is a generic anxiety and depression scale developed >30 years ago. It contains 14 polytomous items scored on two 7-item subscales for anxiety and depression. Higher subscale scores

indicate a presence of anxiety or depression. The HADS and mRS were used to characterize the sample and to investigate differential item functioning (DIF) of the PM-Scale.

Data analysis

Rasch analysis and item selection strategy

Patients' responses to the experimental version of the PM-Scale were analyzed using the RUMM2030 Rasch analysis package[21,a] using unrestricted partial credit parameterization. Rasch analysis involves the formal testing of questionnaire data against a probabilistic model developed by the Danish mathematician Georg Rasch. The applications of the model and its advantages have been described in detail in the literature.[22-24] In short, Rasch analysis tests whether ordinal data satisfy the requirements for the construction of interval scale measurement.[22] The model estimates the locations of patients (ie, participation levels) and the location of items and thresholds (ie, relative difficulty) on a common underlying unidimensional and linear scale of participation.[25] Based on the estimated locations, the expected response of each patient to each item can be computed and compared with the actual response to determine how well the observed data fit the model requirements of order, invariance, and unidimensionality.[26] The level of significance was set at .05.

During successive analyses, the following criteria were used to select items:

1. *Missing data:* Items that had missing response ≥20% were considered as irrelevant to patients' life situations.
2. *Category and threshold discrimination:* For each of the 100 items, the 3 categories of response defined 2 consecutive thresholds: 1 threshold between "not at all" and "weakly" and another threshold between "weakly" and "strongly." A threshold corresponds to the participation level at which a patient has an equal probability of choosing 2 adjacent categories for an item with a given difficulty. When thresholds are reversed, patients with higher participation levels may choose a lower category than do patients with lower participation levels. Reversed thresholds reflect improper discrimination of response categories. Items with reversed thresholds were deleted.
3. *Item fit statistics:* Individual item fit was examined by assessing the deviation of observed scores from the modeled expected scores through fit residual distributions and the χ^2 statistic. Items with fit residuals outside the range of ±2.5 were considered to exhibit misfit. Items with fit residual values close to 0 were considered to have the best fit. The χ^2 probability statistic provided another index of fit. Significant probability values indicated unexpectedly high residuals for an item.[22,27] Item fit was also confirmed graphically by inspection of the item characteristic curve. Items showing large discrepancies between observed and expected responses were considered to be less likely to fit the model. Misfitting items were removed on the basis of statistical and graphical evidence.
4. *DIF:* This measure was used to check the invariance of the scale in terms of 6 personal factors: sex (female vs male), time since stroke onset (≤6mo [recent] vs >6mo [chronic]), level of disability (mRS score, ≤2 [minor] vs >2 [moderate to severe]), depression state (HADS score, ≥10 [depression] vs <10 [no depression]), country (Benin vs Burundi), and age (≤60y [median] vs >60y). Items showing significant DIF for any factor were removed.
5. *Response dependency:* This measure links responses to different items once the main underlying trait has been factored out, and it might artificially inflate reliability.[22,28] Response dependency was investigated by examining the correlation matrix of item residuals. When residuals for 2 items were highly correlated (r>0.3),[29] a patient's response to one item was considered to influence the response to the other item and one of the items was removed.

The resulting scale is defined in logits (log-odds units), a unit defined as the natural logarithm of the odds ratio for participation in any situation described by an item relative to the average item difficulty, conventionally set at 0 logit. A progression of 1 logit indicates an increase in the odds of participation by a factor of $e^1=2.71$. The centile scale provides another linear and more common interpretation, where 0 represents the lowest level of participation and 100 represents the highest level of participation.

Scale reliability

The internal consistency of the PM-Scale was examined by computing the person separation index (PSI; range, 0−1), which is interpreted much like Cronbach α[22,30] and indicates the extent to which distinct levels of participation can be distinguished in the sample.[31,32] To be useful, the scale must enable separation of individuals into at least 2 strata.[33] The test-retest reliability of the PM-Scale was investigated with a subsample of 151 patients who underwent a second evaluation within 2 weeks using the entire set of 100 experimental items. The retest sample belongs to the initial sample of 276 patients. They were composed of survivors who agreed to continue their involvement in the study. The resulting sets of item difficulty and individual location were compared to evaluate consistency over time.

Results

Sample characteristics

Two hundred sixteen patients from Benin and 60 patients from Burundi met the inclusion criteria and agreed to participate in the study. The sample's characteristics are presented in table 1.

Item selection

None of the experimental 100 items of the PM-Scale has missing response ≥20%, but 31 items showed reversed thresholds and were removed. Of the 69 remaining items, 47 were removed due to issues of fit to the model. None of the remaining items presented a significant differential functioning regarding the sample characteristics; the residual correlations between items were ≤0.3, and the 3 rating categories were well discriminated. Consequently, 22 items were selected for the final version of the PM-Scale.

Final version of the PM-Scale

Description of the scale

The final 22-item PM-Scale demonstrated excellent overall fit for items (mean, −0.04±1.19) and persons (mean, −.21±.85). A nonsignificant item-trait interaction ($\chi^2_{66}=80.58$; $P=.11$) indicated that the hierarchy of item difficulty did not vary across the scale. Table 2 lists the estimated item difficulty, associated SEs, and fit

Table 1 Sample's characteristics

Characteristic	Mean ± SD (95% CI) or n (%)	Median (Range)
Age (y)	59±11 (57–60)	57 (18–84)
Benin	58±10 (57–60)	60 (35–82)
Burundi	57±15 (53–61)	58 (18–84)
Sex		
Male	157 (57)	NA
Female	119 (43)	NA
Side of hemiparesis		
Right	130 (47)	NA
Left	146 (53)	NA
Time since stroke (mo)	20±16 (3–32)	5 (0–62)
mRS score		4 (1–5)
≤2	86 (31)	2 (1–2)
>2	190 (69)	3 (3–5)
HADS score		8 (0–22)
<10	184 (67)	4 (0–9)
≥10	92 (33)	15 (10–22)

Abbreviations: CI, confidence interval; NA, not applicable.

statistics. Items are ordered according to difficulty, from the easiest ("understand a gesture of goodbye," −3.79 logits) to the most ("occupy a position of responsibility in my religion organization," 5.02 logits) difficult. The data also indicate that the PM-Scale conceptually covered all 9 ICF domains of participation.

Figure 1 depicts the structure and targeting of the 22-item PM-Scale to the level of participation in our sample. Figure 1A shows the distribution of patient locations on the scale (range, −5.73 to 5.41 logits). Only 1 patient responded "not at all" to all items, and none responded "strongly" to all items. Therefore, the scale is well targeted, with no significant floor or ceiling effect. A patient with an estimated participation level of 0 logit (50 centiles) would be expected to participate "strongly" in the 6 easiest items, "weakly" in the 12 average items, and "not at all" in the 6 most difficult items (see fig 1B). The range of measurement of the PM-Scale was −6.56 to 6.51 logits, that is, 0 to 100 centiles (see fig 1C).

Figure 2 presents the DIF plot of the PM-Scale as a comparison of the hierarchy of the item difficulty, rated in 6 dichotomous subgroups according to time since stroke (see fig 2A), state of depression (see fig 2B), level of disability (see fig 2C), sex (see fig 2D), age (see fig 2E), and country (see fig 2F). No significant difference in the hierarchy of the item difficulty was found for these 6 criteria in our sample ($P>.05$).

Reliability of the PM-Scale

The PM-Scale showed good reliability (PSI, .93) and excellent reproducibility (fig 3). The item hierarchy (see fig 3A) was invariant across time ($r=.99$; $P<.001$), and patient locations (see fig 3B) were consistent over time ($r=.96$; $P<.001$).

Table 2 Item calibration and individual item fit statistics of the PM-Scale

Item	Location (Logit)	SE (Logit)	Fit Statistics: Fit Residual	χ^2	*df*	χ^2 Probability	ICF Participation Domain: d1	d2	d3	d4	d5	d6	d7	d8	d9
1. Understand a gesture of goodbye	−3.79	.20	0.20	4.35	3	.23			*						
2. Clearly understand ideas of others	−3.18	.17	−0.20	2.89	3	.41			*						
3. Express my gratitude to someone	−2.47	.19	−1.57	2.38	3	.50							*		
4. Perform simple mental arithmetic (eg, 10+10)	−2.15	.15	2.30	5.65	3	.13	*								
5. Choose clothing appropriate to the climate	−1.98	.18	−0.75	0.77	3	.86					*				
6. Know how to express my disagreement in a proper way	−1.96	.18	1.23	5.78	3	.12							*		
7. Go to the hospital for care	−1.39	0.14	0.90	0.77	3	.86				*					
8. Choose my occupations based on priorities	−1.22	.14	−0.70	4.80	3	.19		*							
9. Choose my job based on my physical abilities	−0.97	.13	−1.23	7.39	3	.06		*							
10. Have hope in my future	−0.83	.16	−0.18	3.36	3	.34		*							
11. Have confidence in myself	−0.77	.13	1.75	2.68	3	.44		*							
12. Have a clean physical appearance	−0.36	.13	1.42	2.29	3	.51					*				
13. Keep my accounts	0.71	.12	−0.93	6.56	3	.09								*	
14. Clearly understand the content of a letter	0.86	.18	−0.17	3.01	3	.39			*						
15. Have a balanced and varied diet	0.86	.14	1.91	6.81	3	.08					*				
16. Involve myself in the decision making of my entourage	1.50	.13	−0.85	6.02	3	.11							*		
17. Help people find a solution to a crisis	1.53	0.13	−0.18	2.06	3	.56		*							
18. Participate in caring for my children or grandchildren	1.91	.15	0.74	3.48	3	.32						*			
19. Speak to an audience	2.02	.14	−2.00	3.36	3	.34			*						
20. Participate in religious feasts	2.82	.15	−0.99	3.02	3	.39									*
21. Engage myself in a neighborhood association	3.86	.19	−0.57	1.99	3	.58									*
22. Occupy a position of responsibility in my religion organization	5.02	.27	−0.94	1.15	3	.76									*

Abbreviations: d1, learning and applying knowledge; d2, mental functions in general tasks and demands; d3, communication; d4, mobility; d5, self-care; d6, domestic life; d7, interpersonal interactions and relationships; d8, major life areas (employment and economic life); d9, community, social, and civic life * belongs to.

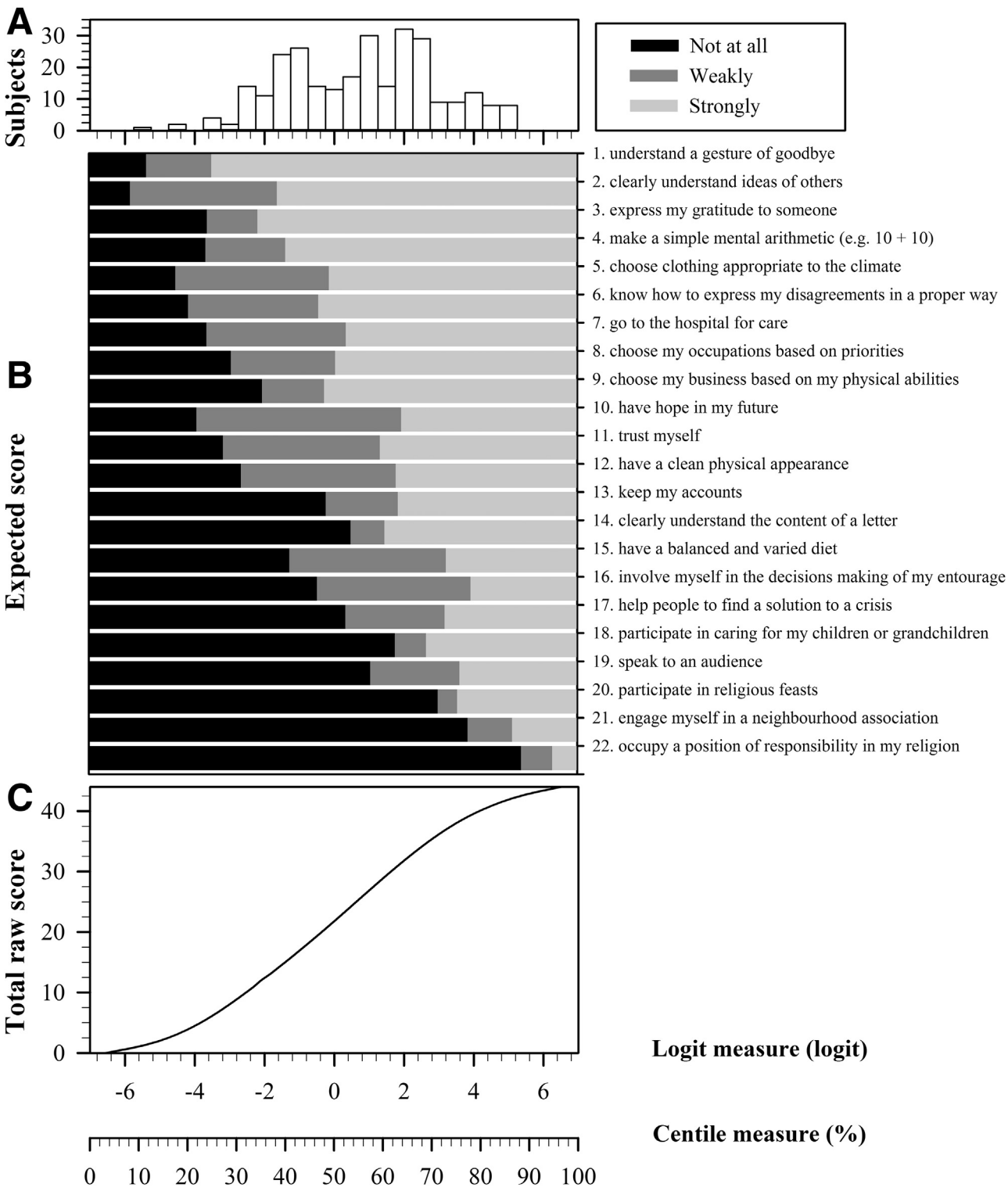

Fig 1 Structure and targeting of the PM-Scale presented in 3 panels: (A) distribution of patient participation measures; (B) threshold map indicating patient's expected response for each item as a function of its participation level; and (C) relationship between the ordinal raw scores and the corresponding linear measures.

Discussion

This study aimed to investigate the psychometric properties of the PM-Scale, a new tool based on the ICF framework that was designed to measure participation after stroke in Africa. Data from 276 patients with stroke in Benin and Burundi were analyzed using the Rasch model. From an initial set of 107 items, 7 were removed because of content validity issues and 78 were removed because of a lack of discrimination of the response categories or because of a lack of fit to the Rasch model during the calibration process, leading to

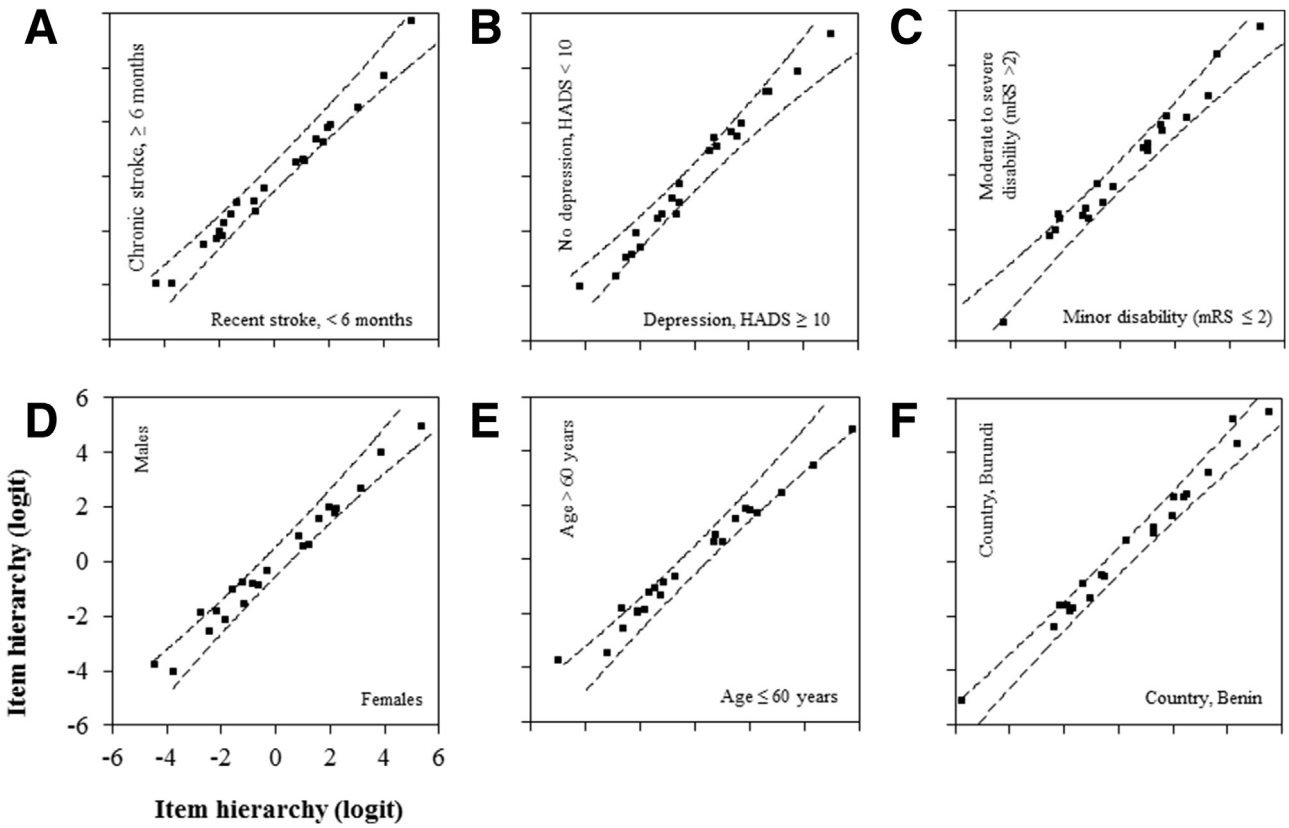

Fig 2 Invariance of the PM-Scale tested by comparing the hierarchy of item difficulties in dichotomous patient subgroups according to 6 criteria: (A) time since stroke; (B) state of depression; (C) level of disability; (D) sex; (E) age; and (F) country. For each criterion, more difficult items are in the top right. Dotted lines indicate 95% confidence intervals of the ideal invariance. Items within dotted lines were ranked with similar hierarchy in patient subgroups. No significant DIF was observed despite the minor exceptions of items lying at the 95% confidence interval boundary.

the final version of 22 items scored on a 3-level scale ("not at all," "weakly," "strongly"). The analyses investigated the appropriateness of category and threshold discrimination, unidimensionality, reliability, and invariance of item hierarchy. The results showed good overall and individual item and person fits to a unidimensional scale, a good reliability index, and good targeting of the scale to the sample. Item hierarchy was also stable between successive evaluations and invariant across selected demographic and clinical factors.

The PSI of the PM-Scale was .93, indicating that the scale is reliable, because ~93% of measurement variance was not due to random errors.[27,28] In clinical practice and research settings, the scale may thus enable distinction of at least 5 strata of significantly different participation levels after stroke. In addition, examination of the test-retest reliability of the scale with 151 patients who were assessed twice showed excellent reproducibility ($r \geq .96$; $P < .001$). The levels of participation measured in our sample of 276 patients ranged from −5.73 to 4.78 logits, but the minimum and maximum levels of the measurement of the PM-Scale were −6.56 to 6.51 logits. Pratically, these results means that the PM-Scale was well targeted to our sample and has the potential for measuring participation beyond the levels encountered in this study. To enable widespread and easy use of the PM-Scale in clinical practice and research settings, we have provided a conversion axis for the transformation of raw scores into interval measures (logits and centiles). However, the conversion is useful only when no data are missing. For cases of missing responses, online analysis is available at www.rehab-scales.org.

The reference framework for this study was the ICF, which classifies participation into 9 domains. We evaluated how well the final version of the PM-Scale represented this conceptual framework by linking each item to the corresponding ICF participation domain. The 22 items of the PM-Scale covered all 9 ICF domains. The content of the hierarchical scale indicated that more difficult items were related predominantly to community, social, and civic life (3 items); interpersonal interactions and relationships (1 item); and domestic life (1 item). The less difficult items were related to communication (2 items), interpersonal interactions and relationships (2 items), learning and applying knowledge (1 item), and self-care (1 item). Our results are consitent with those of previous participation measures. For instance, Heinemann et al[11] reported that in the Participation Enfranchisement Scale, more difficult items were related to community, social, and civic life (eg, "I have a say in community decisions"; "I do things to improve my community"; "I contribute to the general well-being of my community"). Furthermore, Bouffioulx et al[9] found for the SATIS-stroke scale that the item "Participating in spoken exchange of information with your entourage" (communication) is one of the easiest whereas the item "Choosing appropriate clothes" (self-care) was among the most difficut items. This indicates that overall, the same item difficult hierarchy is often found for the participation scales. Our findings also suggest that improvements in participation levels of patients with stroke in Africa communities as well as elswhere requires particular attention to situations demanding community, social, and civic involvement. Beyond

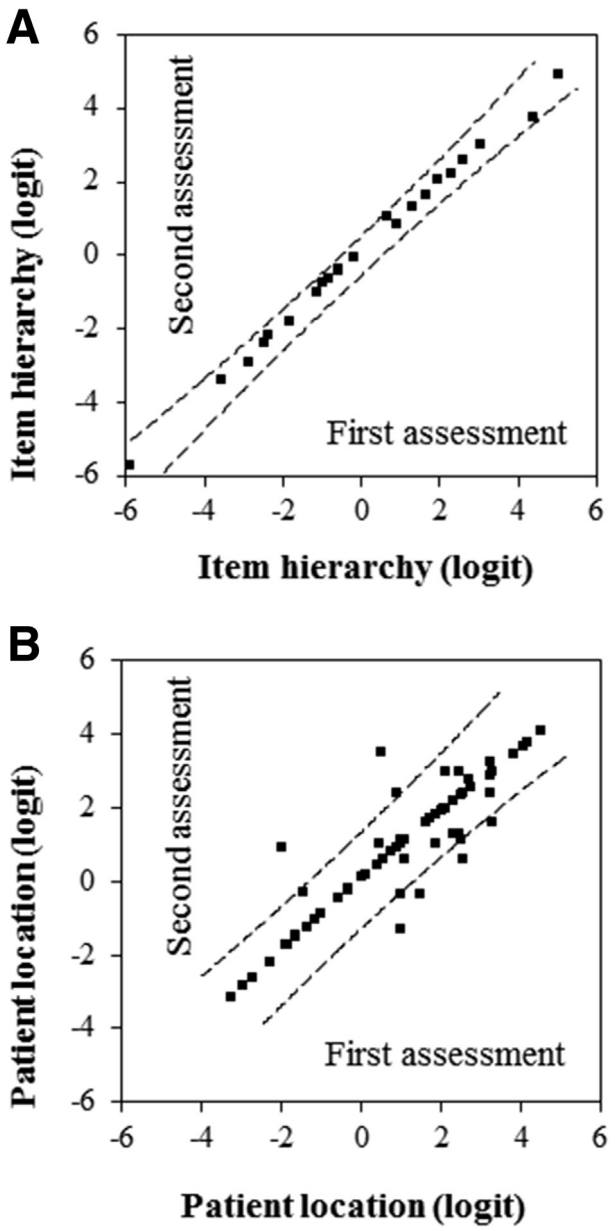

Fig 3 Test-restest reliability of the PM-Scale illustrated by the reproducibility of the (A) item hierarchy and (B) patient location between the first and second assessments. In both panels, the 95% confidence interval of the ideal invariance is indicated by dotted lines.

activities of daily living and the level, frequency, and/or severity of actual health problems, the measurement of participation aims to quantify a patient's performance and perceived experience in social roles as well as in mental and emotional states. The concept of participation lies beyond the disease-impairment continuum, and several studies[34] have suggested that participation outcomes after stroke are likely to be more relevant to the patient than impairment itself. Accordingly, the assessment of participation in patients with chronic diseases remains an issue of particular importance, as treatment may be deemed successful despite poor psychosocial functioning. For instance, patients with stroke who are fully independent according to Barthel Index scores may nevertheless experience limitations in areas such as employment and leisure or in psychosocial aspects of their lives.[35]

Sociocultural differences between continents and other contextual factors need to be taken into account when measuring latent variables such as participation. Therefore, items or questions that are important to capture the construct of participation in the population with stroke through legacy measures in Europe, for instance, might not be relevant for those living elsewhere. Thus, our scale contains items concerning participation in religious feasts, engagement in neighborhood associations, and the holding of positions of religious responsibility, which are important in the African context. These results are consistent with previous studies[36] that found that the main environmental factors likely to influence participation after stroke in Africa are related to recreational, productive/creative (work and employment), social (associative and religious life), and cognitive leisure activities.

The evaluation of the effects of stroke on patients' participation in the African population has not yet generated much interest in the literature and in practice. In addition to being a disease-specific and Rasch-built scale with good psychometric properties, the PM-Scale has the advantage of cross-country validity. The 22 PM-Scale items describe common situations for community-dwelling patients with stroke in a West African country (Benin) and an East African country (Burundi). It provides an equal basis for the monitoring of social participation after stroke in the 2 areas and could be useful in multicenter studies.

Study limitations

The present study focused on the development and validation of the PM-Scale. We did not evaluate the ability of this scale to measure changes in participation resulting from spontaneous or posttreatment recovery. This particular property, called *responsiveness*, should be investigated in future studies.

Conclusions

The PM-Scale is a valid, unidimensional, linear, and invariant ICF-based and Rasch-built scale designed to assess participation after stroke in Africa. It consists of 22 items scored on a 3-level scale. The PM-Scale is easy to administer and takes no more than 5 minutes to complete. The PM-Scale was administered in face-to-face interviews, allowing the evaluator to provide oral explanations to illiterate patients when needed. However, future studies should analyze the consistency between self-report, proxy-respondent, and face-to-face versions of the PM-Scale and the ability of the scale to detect changes over time.

Supplier

a. RUMM2030; RUMM Laboratory Pty Ltd.

Keywords

Africa; Assessment; Rehabilitation; Stroke

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