Applicability of International Classification of Functioning, Disability and Health-based participation measures in stroke survivors in Africa: a systematic review

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To appraise available International Classification of Functioning, Disability and Health (ICF)-based tools for the measurement of participation after stroke and to examine their applicability in the African sociocultural context. Pubmed/Medline, Science Direct, Cochrane Library, and Hinari databases were systematically searched. The literature search was limited to studies published in the English or French language from January 2001 up to May 2019. Two reviewers independently screened all identified studies and selected eligible articles. Disagreements about inclusion or exclusion of studies were resolved by consensus. Two reviewers independently extracted the psychometric properties of each instrument using the Consensus-based Standard for the Selection of Health Measurement Instruments checklist and examined the methodological quality of each selected study using the MacDermid checklist. A total of 1030 articles were systematically reviewed for relevance, yielding 22 studies that met inclusion criteria. These studies were related to nine participation tools. The MacDermid scores ranged from 13 to 21 out of 24. The number of investigated psychometric properties and the number of ICF participation domains covered by each tool varied among studies. This systematic review revealed

Introduction

Stroke ranked as the second most common cause of death worldwide and the most common cause of long-term disability in adults (Feigin *et al.*, 2017). The Global Burden of stroke 2017 study showed that although age-standardized rates of stroke mortality have decreased worldwide in the past two decades, the absolute numbers of people who have a stroke every year, live with the consequences of stroke, and die from their stroke are increasing (Feigin *et al.*, 2017). In sub-Saharan Africa, the pooled prevalence of stroke yielded an estimate of 3.5 per 1000 people (Ezejimofor *et al.*, 2016). This statistic is predicted to increase annually by 12% (Ezejimofor *et al.*, 2016).

Disability after stroke results from complex and dynamic interactions between impairments and contextual barriers, which could hinder individuals' participation in society (Adoukonou *et al.*, 2018a; Kossi *et al.*, 2019). The International Classification of Functioning, Disability,

nine ICF-based tools for the measurement of participation after stroke. We examined the content of these tools and provided valuable information that can be used to guide researchers in Africa in their selection of the most appropriate tool for the measurement of participation after stroke. *International Journal of Rehabilitation Research* XXX: 000–000 Copyright © 2019 Wolters Kluwer Health, Inc. All rights reserved.

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and Health (ICF) defines participation as an individual's involvement in life situations (WHO, 2001). This societal perspective of functioning includes situations involving mental functions of general tasks and demands, learning and applying knowledge, communication, mobility, selfcare, domestic life, interpersonal interactions, and community, social, and civic life.

The ability to be engaged and interact socially with others, such as relatives, siblings, and colleagues, may constitute a factor of social reintegration after a long-term disability (Jansen *et al.*, 2012; Kossi *et al.*, 2016; Kossi and Thonnard, 2018; Kossi *et al.*, 2019). Therefore, social and cultural environments remain important factors throughout the rehabilitation process after a stroke (Kossi *et al.*, 2018). A central issue is that the nature and complexity of a stroke patient's environments change from one culture to another (Lundgren-Nilsson *et al.*, 2005). As a consequence, an individual's perception of what constitutes ideal participation may be influenced by life experiences and adaptation in the context of a changing environment (family, community, society, services, and health policies). Items or questions that are important to capture these concepts in stroke patients living in one location might not be relevant for stroke patients living elsewhere. For example, a stroke-specific participation questionnaire that has been developed (SATIS-Stroke) (Bouffioulx *et al.*, 2008) or adapted (Reintegration to Normal Living Index) (Daneski *et al.*, 2003; Pang *et al.*, 2011) for use in Europe might not be useful as a practical tool in Africa until its applicability has been checked (Lundgren-Nilsson *et al.*, 2005).

In practice settings, a conceptual approach of participation that is congruent with the social and cultural contexts is important to guide the various stages of health service provision, including assessment, goal setting with individuals, program planning for individuals and groups, intervention, and evaluation of program effectiveness (McHorney, 1999; van der Mei et al., 2007; Adoukonou et al., 2018b). At each of these stages, quantitative or/and qualitative data can be collected (preintervention and postintervention) by appropriate measurement tools. Fortunately, more attention is paid to stroke rehabilitation and various instruments have been dedicated to the assessment of participation in stroke patients (Dalemans et al., 2010; Heinemann et al., 2011; Park and Choi, 2014). However, most of these instruments have been developed in a Western context, and the extent to which these instruments are suitable in the African context needs to be investigated. This systematic review aimed to identify and appraise existing ICFbased tools for the measurement of participation after stroke and to evaluate their applicability in Africa.

Methods

Study selection

A comprehensive search of several electronic databases, including *Pubmed*/*Medline*, *Science Direct*, *Cochrane Library*, and Hinari, was conducted in December 2018 and updated in May 2019. Search terms were generated according to the Participant, Intervention, Comparison, Outcome acronym of the Cochrane Handbook for Systematic Reviews of Interventions (Higgins et al., 2011). Detailed search strategy with Medical Subject Heading terms, free textwords and key terms used in each database is presented in Appendix 1. All identified articles were exported to Zotero, and duplications were removed. The first and second authors (O.K. and E.R.A.) independently screened titles and abstracts of all unique records for relevance. Full texts of selected papers were reviewed. We also performed a hand search of the studies cited in the reference sections of relevant articles and previous reviews that addressed participation tools. To be included in this review, studies had to meet the following criteria: (1) was published in 2001 or later in English or French language and (2) reported on at least one stroke-specific participation measure. We limited the date of publication to 2001 in order to capture the WHO's concepts of participation. Consensus about the selection process and methodological rating was achieved between all authors before studies selection and rating. The selection process of relevant articles is shown in the PRISMA flowchart (Fig. 1).

The methodological design of studies was assessed using the MacDermid checklist, a 12-criterion form assessing the methodological design of studies examining the measurement properties of outcome measures (MacDermid et al., 2009). Psychometric data of selected tools were checked using the Consensus-based Standard for the Selection of Health Measurement Instruments (COSMIN) checklist (Mokkink et al., 2010a). The COSMIN checklist contains nine boxes, each dealing with one measurement property (internal consistency, reliability, measurement error, content validity, construct validity, criterion validity, responsiveness, and interpretability). Each box contains five to 18 items that can be used to check whether a study on a specific measurement property meets the standard for good psychometric quality (Mokkink et al., 2010b).

In order to examine the extent to which each instrument captures the WHO's concepts of participation, we linked items to the nine domains of participation described in the ICF framework (WHO, 2001). Selections and ratings were compared with regard to agreement and disagreement. Differences were discussed until consensus was reached between the first and second authors.

Results

Databases

A total of 1030 unique records of possible interest were found in the electronic databases. After the titles and abstracts were screened and full texts were considered, 22 articles describing nine different participation tools were included in the qualitative analysis (Fig. 1). These participation instruments are named below, and each instrument is briefly described in Table 1.

Identified instruments

Based on articles published from 2001, this review identified nine participation measures for stroke patients, including: WHODAS II in stroke (Schlote *et al.*, 2009; Küçükdeveci *et al.*, 2013), London Handicap Scale (Westergren and Hagell, 2006; Kutlay *et al.*, 2011; Park and Choi, 2014), Community Integration Questionnaire (CIQ) (Dalemans *et al.*, 2010; Liu *et al.*, 2014), SATIS-Stroke (Bouffioulx et al., 2008, 2010; Pereira *et al.*, 2019), Reintegration to Normal Living Index (RNLI) (Tooth *et al.*, 2003; Daneski *et al.*, 2003; Pang *et al.*, 2011;), Participation Enfranchisement (Heinemann *et al.*, 2011), Subjective Index for Physical and Social Outcome (SIPSO) (Trigg and Wood, 2003; Kersten et al., 2004, 2010; Kwong *et al.*, 2017; Teale *et al.*, 2013), Participation Measurement Scale (PM-Scale) (Kossi and Thonnard,



Flowchart of articles identification and selection process according to PRISMA guidelines.

2018; Kossi *et al.*, 2018), and Community Participation Activation Scale (CPAS) (Lee *et al.*, 2018).

Methodological design of analyzed studies

Methodological quality scores of the studies, as evaluated with the MacDermid checklist, are summarized in Table 2. The scores ranged from 13 to 21 out of 24 with a median value of 18. The most fulfilled criteria were related to the (1) scope of psychometric properties; (2) analyses for each hypothesis; (3) statistical tests conducted; and (4) axillary analyses beyond point estimates, while the less fulfilled criteria were related to the (1) follow-up; (2) sample size; and (3) clinical recommendations.

Psychometric properties of identified instruments

Table 3 presents the psychometric properties investigated in each instrument, as extracted using the COSMIN checklist. Overall, the content validity of the included instruments has been checked. The construct validity and the cross-cultural adaptation was investigated in seven out of the nine instruments. The internal consistency was also reported for all the instruments. Information about differential item functioning were provided for five instruments (Bouffioulx *et al.*, 2010; Heinemann *et al.*, 2011; Küçükdeveci *et al.*, 2013; Kossi *et al.*, 2018; Lee *et al.*, 2018). The test–retest reliability was not reported for four instruments (Heinemann *et al.*, 2011; Küçükdeveci *et al.*, 2013; Park and Choi, 2014; Lee *et al.*, 2018). Finally, three of the 22 included studies reported the instrument's responsiveness (Trigg *et al.*, 1999; Bouffioulx *et al.*, 2010; Kossi and Thonnard, 2018).

Included instruments and the International Classification of Functioning, Disability and Health's participation domains

Table 4 shows the link between each tool's items and the ICF's nine domains of participation. The number of the domains covered by the instruments varies from four to nine, with a median distribution of seven domains. Two tools covered all the nine domains of the ICF (Bouffioulx *et al.*, 2008; Kossi *et al.*, 2018). All the instruments contain items

Table 1 Description of poststroke participation measures published after the International Classification of Functioning, Disability and Health release in 2001

Participation measure	Authors (year) and country of validation of the stroke version	Administration procedure of the stroke version	Number of items (and response cate- gories per item)
CIQ	Dalemans et al. (2010), Liu et al. (2014), United Kingdom, China	Face-to-face interview	15 ^a (3)
CPAS	Lee et al. (2018), USA	Face-to-face interview/by phone	25 (4)
LHS	Westergren and Hagell (2006), Kutlay et al. (2011), Park and Choi (2014),	Face-to-face interview	6 ^a (6)
	Republic of Korea, Turkey, Swedish		
Participation enfranchisement	Heinemann et al. (2011), USA	Interview by phone	19 ^a (4)
PM-Scale	Kossi <i>et al.</i> (2018), Benin	Face-to-face interview	22 (3)
RNLI	Daneski <i>et al.</i> (2003), Pang <i>et al.</i> (2011), UK, China	Postal, self-report, Proxy	11ª (2)
SATIS-Stroke	Bouffioulx et al. (2008), Pereira et al. (2019), Belgium, Brazil	Self-report	36 (4)
SIPSO	Trigg and Wood (2003), Kwong et al. (2017), UK, China	Postal, self-report, Proxy	10 (5)
WHODAS II	Schlote et al. (2009), Küçükdeveci et al. (2013), Germany, Turkey	Face-to-face interview, proxy	36 ^a /32 (5)

CIQ, Community Integration Questionnaire; CPAS, Community Participation Activation Scale; LHS, London Handicap Scale; PM-Scale, Participation Measurement Scale; RNLI, Reintegration to Normal Living Index; SIPSO, Subjective Index of Physical and Social Outcome; WHODAS II, World Health Organization Disability Assessment Schedule in stroke.

^aAlso used as generic version for other diagnoses.

Table 2 Methodological quality of studies, assessed by the MacDermid critical appraisal tool

		MacDermid critical appraisal criteria												
Study	Related instrument	C1	C2	СЗ	C4	C5	C6	C7	C8	C9	C10	C11	C12	Total score/24 (%)
Bouffioulx et al. (2008)	SATIS-Stroke	2	2	1	2	1	2	2	2	2	2	2	1	21 (87.5)
Kucukdeveci et al. (2013)	WHODAS II	2	2	2	2	1	0	2	2	2	2	2	2	21 (87.5)
Pereira et al. (2019)	SATIS-Stroke	1	2	1	2	2	2	2	2	2	2	1	1	20 (83.3)
Liu et al. (2014)	CIQ	2	2	2	2	0	0	2	1	2	2	2	2	19 (79.2)
Park and Choi (2014)	LHS	2	2	1	2	1	0	2	2	2	2	2	1	19 (79.2)
Kossi <i>et al.</i> (2018)	PM-Scale	2	2	1	2	1	0	2	2	2	2	2	1	19 (79.2)
Trigg et al. (1999)	SIPSO	1	2	2	2	1	0	1	2	2	2	2	2	19 (79.2)
Dalemans et al. (2010)	CIQ	2	2	2	2	1	0	2	2	2	2	0	1	18 (75.0)
Pang et al. (2011)	RNLI	2	2	1	2	1	0	1	2	2	2	2	1	18 (75.0)
Schlote et al. (2009)	WHODAS II	2	2	2	2	1	0	1	1	2	2	2	1	18 (75.0)
Kutlay <i>et al.</i> (2011)	LHS	2	1	2	1	1	0	1	1	2	2	2	2	17 (70.8)
Heinemann et al. (2011)	Participation enfranchisement	2	1	1	2	1	0	2	2	2	2	1	1	17 (70.8)
Daneski <i>et al.</i> (2003)	RNLI	1	1	1	2	1	2	2	1	2	1	1	2	17 (70.8)
Lee et al. (2018)	CPAS	2	1	1	2	0	0	2	2	2	2	2	1	17 (70.8)
Kwong et al. (2017)	SIPSO	2	2	1	1	0	0	1	1	2	2	2	2	16 (66.7)
Westergren and Hagell (2006)	LHS	1	1	1	1	0	0	1	1	2	2	2	1	13 (54.2)

C1, Relevant background: was the relevant background research cited to define what is currently known about the psychometric properties of the measures under study, and the need or potential contributions of the current research question?; C2, Inclusion criteria: were appropriate inclusion/exclusion criteria defined? C3, Specific psychometric hypotheses: were specific psychometric hypotheses identified? C4, Scope of psychometric properties: was an appropriate scope of psychometric properties considered? C5, Sample size: was an appropriate sample size used? C6, Follow-up: was appropriate retention/follow-up obtained?; C7, Documentation: were specific descriptions provided or referenced that explain the measures and its correct application/interpretation (to a standard that would allow replication)? C8, Standardized administration methods: were administration and application of measurement techniques within the study standardized and did they considered potential sources of error/misinterpretation? C9, Analyses for each hypothesis: were analyses conducted for each specific hypothesis or purpose? C10, Statistical tests conducted to obtain point estimates of the psychometric property? C11, Axillary analyses beyond point estimates: were appropriate ancillary analyses were done to describe properties beyond the point estimates (confidence intervals, benchmark comparisons, SEM/MID)? C12, Clinical recommendations: were the conclusions/clinical recommendations supported by the study objectives, analysis, and results?

CIQ, Community Integration Questionnaire; CPAS, Community Participation Activation Scale; LHS, London Handicap Scale; PM-Scale, Participation Measurement Scale; RNLI, Reintegration to Normal Living Index; SIPSO, Subjective Index of Physical and Social Outcome; WHODAS II, World Health Organization Disability Assessment Schedule in stroke.

of mobility, interpersonal interactions and relationships, and community, social, and civic life, while only three instruments contain items of learning and applying knowledge (Bouffioulx *et al.*, 2008; Kossi *et al.*, 2018; Lee *et al.*, 2018).

Applicability of the tools in the African sociocultural context

In Table 5, we examined the applicability of each tool in the African sociocultural context. This included the examination of the content of the tools, the administration procedure, and potential differential items functioning. Three out of the nine tools (WHODAS II, RNLI, and SIPSO) offer the possibility of proxy administration (Tooth *et al.*, 2003; Trigg and Wood, 2003; Schlote *et al.*, 2009). For effective applicability in African context, some of these questionnaires would require a prior screening of the items content (Trigg *et al.*, 1999; Daneski *et al.*, 2003; Bouffioulx *et al.*, 2008; Dalemans *et al.*, 2010; Heinemann *et al.*, 2011; Küçükdeveci *et al.*, 2013; Park and Choi, 2014; Lee *et al.*, 2018), an investigation of the differential item functioning (Trigg *et al.*, 1999; Bouffioulx *et al.*, 2008; Dalemans *et al.*, 2013; Lee *et al.*, 2010; Küçükdeveci *et al.*, 2013; Lee *et al.*, 2018), or an investigation regarding the possibility of proxy administration (Bouffioulx *et al.*, 2008; Dalemans

	Conten	t	Cross-cultural	Internal consistency,				Test-retest	
Instrument (authors, year)	validity	Construct validity	validity	(Cronbach's α)	DIF	Floor effect (%)	Ceiling effect (%)	reliability (ICC or k)	Responsiveness
CIO (Dalemans <i>et al</i> ., 2010; Liu <i>et al</i> ., 2014)	Yes	NA	Yes	0.76-0.84	AN	0	0	ICC=0.84-0.96	٨٨
CPAS (Lee et al., 2018)	Yes	RNLI (<i>r</i> =0.41-0.49**)	NA	0.83-0.92	Yes	0	≥72	NA	NA
LHS (Westergren and Hagell, 2006; Kutlay et al. 2011: Park and Choi 2014)	Yes	Barthel Index (r=0.665***), SF-12 (r=0.615***)	Yes	0.85	NA	0	26	AN	AN
PE (Heinemann et al., 2011)	Yes	Persons with/without disability (Chi2=3.88***)	NA	0.91	Yes	NA	NA	NA	NA
PM-Scale (Kossi and Thonnard, 2018; Kossi <i>et al.</i> , 2018)	Yes	AN	Yes	0.93	Yes	0	0	0.96-0.99	0.56≤effect size≤2.13
RNLI (Daneski <i>et al.</i> , 2003; Tooth <i>et al.</i> , 2003; Pang <i>et al.</i> , 2011)	Yes	Barthel Index (r=0.42***); FAI (r=0.69***)	Yes	0.84	NA	NA	NA	≥0.61	NA
SATIS-Stroke (Bouffioulx <i>et al.</i> , 2008; Pereira <i>et al.</i> , 2019)	Yes	Barthel Index (r=0.74**)	Yes	0.94	Yes	-	10	0.98	0.76≤effect size≤1.12
SIPSO (Trigg and Wood, 2003; Kersten et al., 2004, 2010; Teale <i>et al.</i> , 2013; Kwong <i>et al.</i> , 2017)		RNLI (<i>r</i> =0.65–0.76*)	Yes	0.76-0.83	AN	AN	NA	0.38-0.78	0.1 ≤effect size≤0.33
WHODAS II (Schlote <i>et al.</i> , 2009; Küçükdeveci <i>et al.</i> , 2013)	Yes	Modified Rankin Scale (0.41 ≤r≤0.85**)	Yes	0.80-0.99	Yes	NA	NA	NA	AN
*P<0.05; **P<0.01; ***P<0.001. ADL, activity of daily living; CIQ, Community Ir	ntegration) Questionnaire; COSMIN, consens	us-based standa	rds for the selection of l	nealth sta	tus measurement ins	truments (Mokkink <i>et i</i>	//, 2010); CPAS, Com	nunity Participation

consensus-based standard for the selection of health measurement instruments checklist using the mary of psychometric characteristics of participation S In

Activation Scale; DIF, differential item functioning; FAI, Frenchay activities index; ICC, Intraclass Corraltion Cofficient; k, kappa coefficient; LHS, London Handicap Scale; NA, not available; PM-Scale, Participation Measurement Scale; RNLI, Reintegration to Normal Living Index; SF-12, short form health survey; SIPSO, Subjective Index of Physical and Social Outcome; WHODAS II, World Health Organization Disability Assessment Schedule in stroke. WHODAS II: World Health Organization Disability Assessment Schedule in stroke; LHS: London Handicap Scale; CIO: Community Integration Questionnaire; RNLI: Reintegration to Normal Living Index; PE: Participation Enfranchisement; SIPSO: Subjective Index of Physical and Social Outcome; PM-Scale: Participation Measurement Scale; CPAS: Community Participation Activation Scale.

Table 4 Number of International Classification of Functioning, Disability and Health participation domains covered by the questionnaire-based instruments

	ICF participation domains (d)									
Participation measures	d1	d2	d3	d4	d5	d6	d7	d8	d9	Total number of ICF domains covered
CIQ (Dalemans <i>et al.</i> , 2010; Liu <i>et al.</i> , 2014)	NA	1	NA	1	1	1	1	1	1	7
CPAS (Lee et al., 2018)	1	1	1	1	1	NA	1	1	1	8
LHS (Westergren and Hagell, 2006; Kutlay et al., 2011; Park and Choi, 2014)	NA	NA	NA	1	NA	1	1	1	1	5
PE (Heinemann et al., 2011)	NA	1	NA	1	NA	1	1	NA	1	5
PM-Scale (Kossi et al., 2018)	1	1	1	1	1	1	1	1	1	9
RNLI (Tooth et al., 2003; Bouffioulx et al., 2008; Pang et al., 2011)	NA	NA	NA	1	NA	NA	1	1	1	4
SATIS-Stroke (Bouffioulx et al., 2008; Pereira et al., 2019)	1	1	1	1	1	1	1	1	1	9
SIPSO (Trigg et al., 1999; Kwong et al., 2017)	NA	1	1	1	1	1	1	NA	1	7
WHODAS II (Schlote et al., 2009; Küçükdeveci et al., 2013)	NA	1	1	1	1	1	1	1	1	8

d1, learning and applying knowledge; d2, 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.

CIO, Community Integration Questionnaire; CPAS, Community Participation Activation Scale; ICF, International Classification of Functioning, Disability and Health; LHS, London Handicap Scale; NA, not available; PM-Scale, Participation Measurement Scale; RNLI, Reintegration to Normal Living Index; SIPSO, Subjective Index of Physical and Social Outcome; WHODAS II, World Health Organization Disability Assessment Schedule in stroke.

Table 5 Examination of applicability of identified participation measures in the African sociocultural context

Participation measures	Relevance and items functioning regarding the African context	Possible limitations of the adminis- tration procedure in some areas (or patients) in Africa
CIQ	Items are relevant, but some of them may need DIF investigation (i.e., who prepares meals, who does everyday housework, who care for children, who plans social arrangements, and frequency of shopping)	Linguistic and cognitive problems
CPAS	Items are relevant, no obvious problem of discrimination	Linguistic and cognitive problems
LHS	Items are relevant, no obvious problem of discrimination	Linguistic and cognitive problems
Participation enfranchisement	Items are relevant, no obvious problem of discrimination	Linguistic and cognitive problems
PM-Scale	Items are relevant, no obvious problem of discrimination	Linguistic and cognitive problems
RNLI	Items are relevant, no obvious problem of discrimination	No obvious limitation
SATIS-Stroke	Items are relevant, but some of them could need DIF investigation (i.e., to insuring that your rights are respected, participating in food and drink preparation)	Linguistic and cognitive problems
SIPSO	Items are relevant, no obvious problem of discrimination	No obvious limitation
WHODAS II	Items are relevant, no obvious problem of discrimination	No obvious limitation

CIQ, Community Integration Questionnaire; CPAS, Community Participation Activation Scale; DIF, differential item functioning; LHS, London Handicap Scale; PM-Scale, Participation Measurement Scale; RNLI, Reintegration to Normal Living Index; SIPSO, Subjective Index of Physical and Social Outcome; WHODAS II, World Health Organization Disability Assessment Schedule in stroke.

et al., 2010; Heinemann *et al.*, 2011; Park and Choi, 2014; Kossi *et al.*, 2018; Lee *et al.*, 2018)

Discussion

This systematic review aimed to appraise existing tools that measure participation after stroke and to evaluate their applicability in the African sociocultural context. The review included 22 articles related to nine participation measures. Analyses of content validity, administration procedure, psychometric properties, and congruence of each tool with the ICF conceptual framework provided valuable information to facilitate the selection of appropriate instruments for data collection in clinical and research settings in the African sociocultural context. The relatively high total number of articles identified in databases reflects the fact that participation is increasingly recognized as important domains of interest in rehabilitation research (van der Mei *et al.*, 2007; Jansen *et al.*, 2012).

This systematic review shows an overview of the participation instruments available for use in people with stroke. Six of the identified instruments were designed to be administered by face-to-face interview or in interview by phone (Dalemans et al., 2010; Heinemann et al., 2011; Küçükdeveci et al., 2013; Park and Choi, 2014; Kossi et al., 2018; Lee et al., 2018) which may lead to a time-consuming process, especially for questionnaires with a high number of items (Küçükdeveci et al., 2013; Lee et al., 2018). In addition, results from a recent study showed that in many African countries, more notably in Western and Central Africa, a small percentage of adults can read (Smith-Greenaway, 2015). Therefore, an issue of particular relevance when selecting outcome measures, especially for stroke populations in these areas, would be the intended mode of administration of the measures and their suitability for use with proxies. In fact, even if self-administered measures tend to be less resource or time-consuming, linguistic, and readability problems could complicate self-completion for some subjects (Smith-Greenaway, 2015). This applies to the administration of questionnaire-based instruments in African context. Interviewer-administered questionnaires may also be problematic to apply because some stroke patients may be unable to respond in an interview setting due to cognitive problems that are common in stroke survivors. Consequently, the possibility of using proxies (relative or

close friend) seems to be relevant when measuring participation in the Africa context.

Sociocultural realities differ across continents, and such differences need to be considered when measuring latent variables, such as participation. For instance, evidence of invariance of subjects' responses, regardless of socioeconomic and demographic status, and evidence of content validity are crucial for participation measures, as with any outcome measure, to ensure the relevance of their usefulness (D'Olhaberriague et al., 1996; McHorney, 1999). Validity is the extent to which an instrument measures what it is intended to measure (Abanobi, 1986). Content validity refers to the relevance of questions or items of an outcome measure regarding a given construct in a particular context. Content validity would be established by experts judging whether the content was relevant. Through this systematic review, we examined the content of each tool and the administration procedure. Our analyses suggest that two participation measures (CIQ and SATIS-Stroke) may need not only a content adjustment or at least, a formal examination of the differential item functioning or invariance, but also an investigation of the reliability of their administration via proxy-respondent. For instance, five of the 15 items of CIQ were 'who prepares meals', 'who does everyday housework', 'who cares for children', 'who plans social arrangements', and 'frequency of shopping'. In the African context, males are less involved in preparing food, doing housework, and caring for children on a routine basis. Hence, such questions may be less discriminative for male subjects experiencing stroke in Africa, where such items may lead to missing responses for most of respondents.

Through a critical appraisal of each study by the MacDermid checklist, this review offers an overall evidence about the methodological quality of studies that have generated the outcome measures currently used to evaluate participation in patients with stroke. Overall, all of the studies related to participation instruments highlighted good methodological quality, with scores ranging from 13 to 21 out of 24 (Table 2). SATIS-Stroke (Bouffioulx et al., 2008) and WHODAS II (Küçükdeveci et al., 2013) have the highest scores. Sample size calculation and standard requirements for test-retest analyses were the criteria that often missed. However, an excellent score on the MacDermid checklist does not guarantee that the study will produce an assessment tool with perfect psychometric properties. Consequently, evidence of psychometric quality is an important step in the validation of a measurement tool. Evidence of good psychometric properties should constitute a key point in the choice of a tool for clinical and research settings. One of the important psychometric properties of an assessment tool is its internal consistency reported as Cronbach's a for classical analysis or person separation index when Rasch analysis is applied. This reliability index indicates the extent to which distinct levels of participation can be distinguished in a sample (Fisher, 1992; Wright and

Masters, 2002). To be useful, the scale must enable separation of individuals into at least two strata which implies an $\alpha \ge 0.70$ (Wright, 1996; Wright and Masters, 2002). All scales identified in this systematic review fulfilled this requirement. Another important psychometric property is the ability of a scale to detect changes over time, and this is an essential criterion for instrument selection when measuring patient functioning in chronic diseases (Turner et al., 2013). Effect size is often used to characterize the magnitude of the internal responsiveness to change. Effect size can be interpreted by using Cohen's benchmarks, with the magnitude of the changes classified as nonsignificant (effect size < 0.2), small ($0.2 \le$ effect size < 0.5), moderate (0.5 \le effect size < 0.8), or large (effect size ≥ 0.8) (Cohen, 1988). Three of the included studies reported the instrument responsiveness, but SATIS-Stroke (Bouffioulx et al., 2010) and PM-Scale (Kossi and Thonnard, 2018) exhibited moderate to large effect sizes.

To the best of our knowledge, the present systematic review is the first which examined the applicability of participation measures in the African sociocultural context. This review shows that although most of the items included in the nine identified measures were relevant regarding the African context, several of them may need an adaptation or an examination of some psychometric properties such as differential item functioning before being used in Africa as practical tools.

Study limitations

This systematic review has some potential limitations. First, articles were only included if they were published in English or French languages. Some instruments developed or validated in other languages (Spanish, Chinese, Japanese, etc.) may have been missed. Second, the MacDermid scale is a checklist. The total raw score gives an idea of the number of criteria filled by the methodological process underpinning the development or the adaptation of a scale. As a consequence, our classification of the methodological design of the studies does not follow the rules of a linear continuum. Our choice of the MacDermid scale was motivated by the fact that to our knowledge, critical appraisal checklists of the methodology of psychometric studies are scarce.

Conclusion

The present systematic review gives an overview of the ICF-based participation measures available for use in the stroke population and examined their applicability in the African sociocultural context. The information provided in this study can be used to guide researchers and clinicians in Africa in the selection of the most appropriate tool for the measurement of participation in stroke patients.

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Conflicts of interest

There are no conflicts of interest.

Appendix 1. Electronic search strategy

Pubmed (759)

((('Stroke'[Majr:noexp])AND ('Social Participation'[mh]) OR 'Community Participation'[mh] OR 'Community Integration'[mh] OR 'Participation'[ti]) AND ('Outcome Assessment'[Majr:noexp]) OR 'Assessment scale'[ti], OR 'Measurement scale'[ti]) OR 'Participation measurement scale as topic'[mh]))

Science direct (135)

(Stroke) AND (participation, social integration, social participation, community integration) AND (tools, instruments, questionnaire, measurement tools, assessment scale)

Cochrane Library (63)

'Stroke' [Title Abstract Keyword]
 Participation [Title]
 Measurement [Title Abstract Keyword]
 AND 2 AND 3 → 51 Trials

'Stroke' [Title Abstract Keyword]
(Integration, Community, Involvement) [All Text]
(Assessment, Evaluation) [All Text] **1 AND 2 AND 3 → 12 Trials**

Hinary (70)

Stroke [Title]
 Participation [Title]
 Participation [Abstract]
 (Outcome, Assessment) [Title]
 (Outcome, Assessment) [Abstract]
 AND (2 OR 3) AND (4 OR 5) → 19 publications

6. Stroke [Title]
7. Community [Title]
8. Community [Abstract]
9. Measurement [Title]
10. Measurement [Abstract]
6 AND (8 OR 9) AND (9 OR 10) → 48 publications

- 11. Stroke [Title]
- 12. Integration [Title]
- 13. Integration [Abstract]
- 14. Scale [Title]
- 15. Scale [Abstract]

11 AND (12 OR 13) AND (14 OR 15) \rightarrow 3 publications

TOTAL = 1027

References

- Abanobi OC (1986). Content validity in the assessment of health status. *Health Values* **10**:37–40.
- Adoukonou T, Kossi O, Agbetou M, Tchaou B, Agballa G, Houinato DS (2018a). Short term (3 months) prognosis of stroke in parakou. *Neurosci Med* 09:81–93.
- Adoukonou TA, Kossi O, Yamadjako D, Agbétou M (2018b). Restrictions in participation in social life after a stroke among elderly people in Benin. NPG Neurologie Psychiatrie Gériatrie 18:140–148.
- Bouffioulx E, Arnould C, Thonnard JL (2008). SATIS-stroke: a satisfaction measure of activities and participation in the actual environment experienced by patients with chronic stroke. J Rehabil Med 40:836–843.
- Bouffioulx E, Arnould C, Vandervelde L, Thonnard JL (2010). Changes in satisfaction with activities and participitation between acute, post-acute and chronic stroke phases: a responsiveness study of the SATIS-stroke questionnaire. J Rehabil Med 42:944–948.
- Cohen J (1988). *Statistical Power Analysis for the Behavioral Sciences*. Hillsdale: Laurence Erlbaum Associates. p. 1.
- Dalemans RJ, de Witte LP, Beurskens AJ, van den Heuvel WJ, Wade DT (2010). Psychometric properties of the community integration questionnaire adjusted for people with aphasia. Arch Phys Med Rehabil **91**:395–399.
- Daneski K, Coshall C, Tilling K, Wolfe CD (2003). Reliability and validity of a postal version of the reintegration to normal living index, modified for use with stroke patients. *Clin Rehabil* 17:835–839.
- D'Olhaberriague L, Litvan I, Mitsias P, Mansbach HH (1996). A reappraisal of reliability and validity studies in stroke. *Stroke* **27**:2331–2336.
- Ezejimofor MC, Chen YF, Kandala NB, Ezejimofor BC, Ezeabasili AC, Stranges S, Uthman OA (2016). Stroke survivors in low- and middle-income countries: a meta-analysis of prevalence and secular trends. J Neurol Sci 364:68–76.
- Feigin VL, Norrving B, Mensah GA (2017). Global burden of stroke. *Circ Res* **120**:439–448.
- Fisher WJ, 1992. Reliability statistics. Rasch Meas Trans 6:238.
- Heinemann AW, Lai JS, Magasi S, Hammel J, Corrigan JD, Bogner JA, Whiteneck GG (2011). Measuring participation enfranchisement. Arch Phys Med Rehabil 92:564–571.
- Higgins P, Green S, Altman G (2011). Chapter 6: Searching for studies. In: Green S, Higgins JPT, editors. *Handbook for Systematic Reviews of Interventions Version 5.1.0*. The Cochrane Collaboration. Available at: www.training. cochrane.org/handbook.
- Jansen HE, Schepers VP, Visser-Meily JM, Post MW (2012). Social activity one and three years post-stroke. *J Rehabil Med* **44**:47–50.
- Kersten P, George S, Low J, Ashburn A, McLellan L (2004). The subjective index of physical and social outcome: its usefulness in a younger stroke population. *Int J Rehabil Res* 27:59–63.
- Kersten P, Ashburn A, George S, Low J (2010). The subjective index for physical and social outcome (SIPSO) in stroke: investigation of its subscale structure. BMC Neurol 10:26.
- Kossi O, Batcho CS, Adoukonou T, Thonnard JL (2016). Functional recovery after stroke in Benin: a six-month follow-up study. J Rehabil Med 48:671–675.
- Kossi O, Thonnard JL (2018). Tracking changes in participation with participation measurement scale in community-dwelling stroke survivors in Africa. Arch Phys Med Rehabil 99:2238–2243.
- Kossi O, Nindorera F, Batcho CS, Adoukonou T, Penta M, Thonnard JL (2018). Measuring participation after stroke in Africa: development of the participation measurement scale. Arch Phys Med Rehabil 99:652–659.
- Kossi O, Nindorera F, Adoukonou T, Penta M, Thonnard JL (2019). Determinants of social participation at one, three, and six months after stroke in Benin. *Arch Phys Med Rehabil* 25 apr 2019; pii: S0003-9993(19)30263-1. doi: 10.1016/j.apmr.2019.03.020.
- Küçükdeveci AA, Kutlay Ş, Yıldızlar D, Öztuna D, Elhan AH, Tennant A (2013) The reliability and validity of the World Health Organization disability assessment schedule (WHODAS-II) in stroke. *Disabil Rehabil* 35:214–220.
- Kutlay S, Küçükdeveci AA, Yanik B, Elhan A, Oztuna D, Tennant A (2011). The interval scaling properties of the London handicap scale: an example from the adaptation of the scale for use in Turkey. *Clin Rehabil* 25:248–255.
- Kwong PW, Ng SS, Ng GY (2017). An investigation of the psychometric properties of the Chinese (cantonese) version of subjective index of physical and social outcome (SIPSO). *Clin Rehabil* **31**:1538–1547.
- Lee D, Mallinson T, Baum CM, Hammel J (2018). Initial psychometric evaluation of the community participation activation scale. *Can J Occup Ther* 2018 Nov 9:8417418795297. doi: 10.1177/0008417418795297.
- Liu TW, Ng SS, Ng GY (2014). Translation and initial validation of the Chinese (Cantonese) version of community integration measure for use in patients with chronic stroke. *Biomed Res Int* **2014**:623836.

- Lundgren-Nilsson A, Grimby G, Ring H, Tesio L, Lawton G, Slade A, et al. (2005). Cross-cultural validity of functional independence measure items in stroke: a study using rasch analysis. J Rehabil Med 37:23–31.
- MacDermid JC, Walton DM, Law M (2009). Critical appraisal of research evidence for its validity and usefulness. *Hand Clin* 25:29–42.
- McHorney CA (1999). Health status assessment methods for adults: past accomplishments and future challenges. Annu Rev Public Health 20:309–335.
- Mokkink LB, Terwee CB, Knol DL, Stratford PW, Alonso J, Patrick D L, et al. (2010a). The COSMIN checklist for evaluating the methodological quality of studies on measurement properties: a clarification of its content. BMC Med Res Methodol 10:22.
- Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Knol D L, et al. (2010b). The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. Qual Life Res 19:539–549.
- Pang MY, Lau RW, Yeung PK, Liao LR, Chung RC (2011). Development and validation of the Chinese version of the reintegration to normal living index for use with stroke patients. *J Rehabil Med* **43**:243–250.
- Park EY, Choi YI (2014). Rasch analysis of the London handicap scale in stroke patients: a cross-sectional study. J Neuroeng Rehabil 11:114.
- Pereira GS, Silva SM, Júlio CE, Thonnard JL, Bouffioulx E, Corrêa JC F, Corrêa FI (2019). Translation and cross-cultural adaptation of SATIS-stroke for use in Brazil: a satisfaction measure of activities and participation in stroke survivors. *Biomed Res Int* **2019**:8054640.
- Schlote A, Richter M, Wunderlich MT, Poppendick U, Möller C, Schwelm K, Wallesch CW (2009). WHODAS II with people after stroke and their relatives. *Disabil Rehabil* 31:855–864.

- Smith-Greenaway E (2015). Educational attainment and adult literacy: a descriptive account of 31 sub-saharan Africa countries. *Demogr Res* 33:1015–1034.
- Teale EA, Munyombwe TM, Young JB (2013). Scaling properties of the subjective index of physical and social outcome after stroke in a study population unselected by age. Arch Phys Med Rehabil 94:2448–2455.
- Tooth LR, McKenna KT, Smith M, O'Rourke PK (2003). Reliability of scores between stroke patients and significant others on the reintegration to normal living (RNL) index. *Disabil Rehabil* 25:433–440.
- Trigg R, Wood VA (2003). The validation of the subjective index of physical and social outcome (SIPSO). *Clin Rehabil* 17:283–289.
- Trigg R, Wood,VA, Hewer RL (1999). Social reintegration after stroke: the first stages in the development of the subjective index of physical and social outcome (SIPSO). *Clin Rehabil* 13:341–353.
- Turner N, Campbell J, Peters TJ, Wiles N, Hollinghurst S (2013). A comparison of four different approaches to measuring health utility in depressed patients. *Health Qual Life Outcomes* 11:81.
- van der Mei SF, van Sonderen EL, van Son WJ, de Jong PE, Groothoff J W, van den Heuvel WJ (2007). Social participation after successful kidney transplantation. *Disabil Rehabil* **29**:473–483.
- Westergren A, Hagell P (2006). Initial validation of the swedish version of the London handicap scale. *Qual Life Res* 15:1251–1256.
- WHO (2001). International Classification of Functioning, Disability and Health (ICF). Geneva. 2001. Available at: https://www.who.int/classifications/icf/ icf_more/en/.
- Wright BD (1996). Reliability and separation. Rasch Meas Trans 9:472.
- Wright BD, Masters G (2002). Number of person or item strata: (4*separation + 1)/3. Rasch Meas Trans 16:888.