



Participation in community-dwelling stroke survivors in Africa

OYENE KOSSI

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Jury

Chair

Prof. GREGOIRE Jacques

(Institut de Recherche en Sciences Psychologiques, UCL, Belgium)

Supervisor

Prof. THONNARD Jean-Louis

(Institut of Neuroscience, UCL, Belgium)

Co-Supervisor

Dr ADOUKONOU Thierry, Maitre de Conférences Agrégé

(Unité de Recherche et d'Enseignement de Neurologie, UP, Benin)

Members

Prof. TESIO Luigi

(University of Milan, Italy)

Dr PENTA Massimo

(Institut of Neuroscience, UCL, Belgium)

Prof. BLEYENHEUFT Yannick

(Institut of Neuroscience, UCL, Belgium)

Dr ARLNOULD Carlyne

(Haute Ecole de Louvain en Hainaut, Belgium)

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List of publications and communications

Published articles

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Summary

Stroke is among the leading cause of death and chronic disability worldwide. Long-term management of stroke rehabilitation is a great challenge for health systems, particularly in developing countries. Unless appropriate strategies are developed, the economic and social burden of stroke rehabilitation will expand in both low-income and high-income countries. The general focus of this thesis was to contribute in the management of stroke rehabilitation in African countries. To achieve this purpose we firstly investigate the functional recovery during the first 6 months in sample of 68 survivors from the Republic of Benin. Secondly we developed, analyzed the initial psychometric properties and validated a new tool for the measurement of participation after stroke in Africa, named the Participation Measurement Scale (PM-Scale). In a next step, we studied the ability of the PM-Scale to detect changes over time. Finally we explored the relationships between body functions, activity, and participation in a sample of 64 stroke survivors in Benin.

Keywords: Stroke – Rehabilitation – Participation – Measurement

Résumé

Les accidents vasculaires cérébraux (AVC) constituent une cause majeure de décès et de handicap chronique. La gestion à long-terme de la rééducation-réadaptation des cas d'AVC représente un grand défi pour les systèmes de santé, en particulier dans les pays en développement. Si des stratégies bien appropriées ne sont pas développées à court et moyen termes, la charge économique et sociale des AVC risque d'exploser dans les décennies à venir, aussi bien dans les pays pauvres que dans les pays riches. L'objectif général de cette thèse est de contribuer à l'avancement de la réadaptation des personnes victimes d'AVC dans les pays africains. Pour atteindre cet objectif, nous avons dans un premier temps investigué la récupération fonctionnelle post-AVC dans un échantillon de 68 patients recrutés en République du Bénin. Ensuite nous avons développé une nouvelle échelle d'évaluation de la participation après AVC dans le contexte Africain. Cet outil est dénommé Participation Measurement Scale (PM-Scale). Dans l'étude suivante nous avons investigué la sensibilité du nouvel outil à détecter des changements dans le temps. Dans une dernière étude nous avons exploré les relations entre les fonctions organiques, les activités et la participation dans un échantillon de 64 sujets ayant survécu à l'AVC en République du Bénin.

Mots-Clés: AVC – Réadaptation – Participation – Evaluation

General introduction

« La seule limite à nos réalisations de demain sera nos
doutes d'aujourd'hui ».

Franklin Delano Roosevelt



1.1. Conceptual framework of this thesis: The International Classification of Functioning, Disability and Health

The International Classification of Functioning, Disability and Health (ICF) was developed by the World Health Organization (WHO) for application in various aspects of health (WHO 2001). The ICF belongs to the international classifications that provide a framework to code a wide range of information about health (e.g. diagnosis, functioning and disability) and it uses standardized common language permitting communication about health and health care across the world in various disciplines and sciences. The dimensions of ICF are described from the perspective of the body, the individual and society; and can be divided into two parts: (1) Functioning and Disability (Body Functions and Structures, Activities and Participation), (2) Contextual Factors (Environmental Factors and Personal Factors). (Figure 1)

Body functions are the physiological functions of body systems (e.g. mental and psychological functions, voice and speech, etc.), and body structures are anatomical parts of the body such as organs, limbs and their components. Impairments represent a deviation from certain generally accepted population standards in the body structures and functions.

Activity refers to the execution of a task or an action by an individual (WHO 2001). Participation, according to the ICF, is defined as individual's

involvement in life situations, whereas participation restriction is defined as problems individuals may experience in involvement in life situations (WHO 2001). Participation restrictions occur when an individual is unable to carry out his/her social roles, responsibilities, personal wishes, and hobbies due to a disease or illness. The participation restrictions may not be consecutive to body structures and functions only, but may also be due to activity limitations and environmental and/or personal factors.

Participation is a relatively recent concept that deserves much more attention in the last two decades as it is increasingly considered as pivotal to the outcome of successful rehabilitation (Desrosiers et al. 2005). Numerous instruments or measurement tools have been developed that are devoted to the assessment of impairments and functional autonomous. Equal efforts have not been directed towards the comprehensive assessment of participation, being the least often measured of all rehabilitation outcomes (Mellick 2000). The lack of suitable outcome measures on the participatory dimension of the ICF framework spectrum becomes more evident particularly with long-term disability such as that experienced after stroke especially in developing countries.

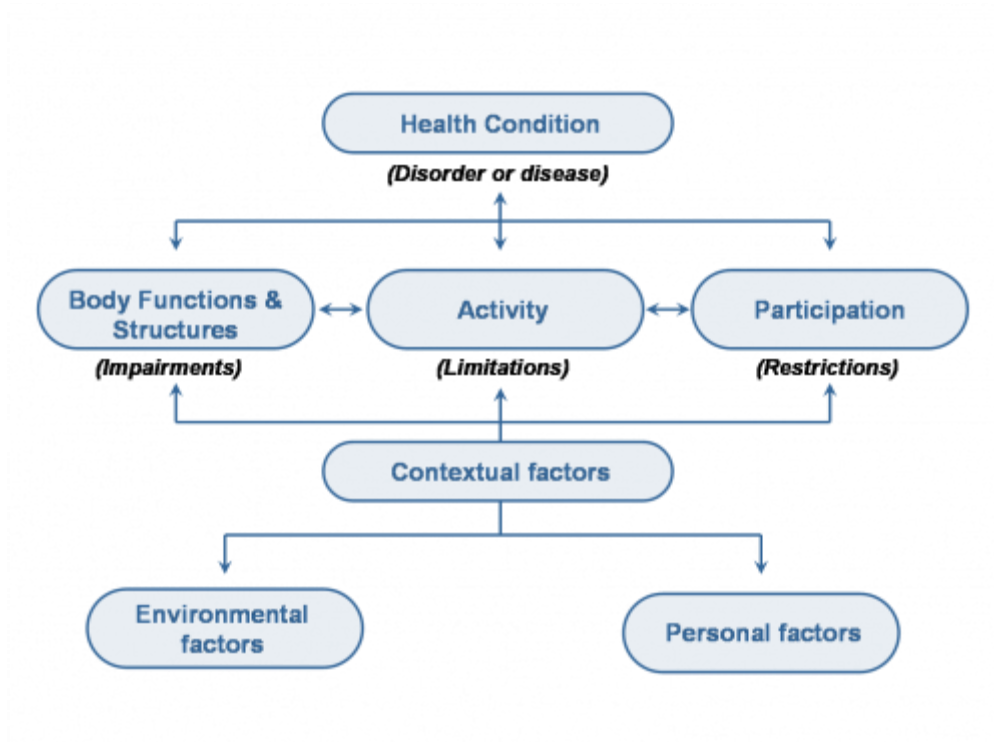


Figure 1: Interactions between ICF dimensions

World Health Organization (2001). International Classification of Functioning, disability and health: ICF. Geneva: World Health Organization.

Contextual Factors represent the complete background of an individual's life and living. They include two components: Environmental Factors and Personal Factors (WHO 2001). Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. These factors are external to individuals and can have a positive or negative influence on the individual's performance as a member of society, on the individual's capacity to execute actions or tasks, or on the

individual's body function or structure. Personal factors are the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health states. These factors may include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, etc. Although personal factors are recognized in the interactive model shown in Figure 1, they are not classified in the ICF at this time. Such factors influence how disability is experienced by the individual and some (eg, age and gender) are commonly included in data collections.

1.2. Stroke and the ICF framework

Stroke is defined by the WHO as a “rapid development of clinical signs of focal or global disturbance of cerebral function, with symptoms lasting more than 24 hours or leading to death and with no apparent non-vascular cause” (WHO 1989). Causes, risk factors, types, and treatments of stroke are described in details in the literature (Roth et al. 2017; Forouzanfar et al. 2017; Mendis et al. 2011; Feigin et al. 2016).

The major consequence of stroke is death. The Global Burden of Stroke (GBS) project found that in 2013 stroke was the second most common cause of deaths (11.8% of all deaths) worldwide, after ischemic heart disease (14.8%). Globally, in 2013 there were almost 6.5 million deaths from stroke (Feigin et al. 2017). A significant increase in absolute numbers

of stroke deaths among younger adults was detected in developing countries, where most of the burden of stroke resided. There was a 20.1% decline in the number of total stroke deaths among younger adults in developed countries, but a 36.7% increase in developing countries. Ironically, there is insufficient information on the current epidemiology of stroke in African countries and other Low and Middle Income Countries (LMICs), where this knowledge is needed most. This is due to the deficient manpower and other resources to fight the epidemic (Owolabi et al. 2015). The first epidemiological studies on stroke in sub-Saharan Africa were hospital based (Osuntokun et al. 1987; Osuntokun et al. 1979; Ezejimofor et al. 2016). However, recent community-based studies in African countries have shown that cerebrovascular diseases represent up to 5–10% of the causes of death, and that the prevalence of important risk factors for stroke (hypertension, diabetes and smoking) is increasing (van der Sande et al. 2001; Wilde et al. 2000; Roth et al. 2017). In Africa, the estimated pooled prevalence of stroke is 3.5 per 1,000, with an annual increase of 12.0% (Ezejimofor et al. 2016).

1.2.1. Impairments after stroke

Apart from the risk of death, people with stroke will experience several types of impairments. Seventy per cent of them will experience arm weakness, and 62% of these will not recovery dexterity in the arm at 6 months post-stroke (Kwakkel et al. 2003). Hypertonicity is present as early as one week post-stroke (de Jong et al. 2011) and affects up to 47% of survivors (Kong et al. 2012). Pain can also occur within one week (Ratnasabapathy et al. 2003) with an incidence up to 49% (Lundstrom et al. 2009). The prevalence of cognitive impairment varies across studies, depending on assessment methods, definitions, or sample characteristics. Neuropsychological assessments often reveals that deficits in executive functioning, attention, mental processing speed, visual perception, and construction ability are common ailments both in subacute and chronic patients(Lesniak et al. 2008) The risk of proceeding cognitive decline and dementia after stroke is often stated (Mijajlovic et al. 2017; Gorelick et al. 2015; Nyenhuis et al. 2002). Yet, several authors have stressed the multiple evolutionary trends in cognitive changes in chronic stroke patients. They found an annual conversion to dementia in 8–13% within the first year after stroke (Gorelick et al. 2015; Nyenhuis et al. 2002; Bertolin et al. 2017).

1.2.2. Activity limitations after stroke

Stroke remains a leading cause of long-term disability (Feigin et al. 2009). Post-stroke consequences include persistent physical deconditioning that worsens functional independence. For example, the exercise capacity of stroke patients is approximately 40% below age- and gender-adjusted norms for sedentary individuals (Ivey et al. 2006; Macko et al. 2001; Kelly et al. 2003). Consequently, stroke survivors are prone to a sedentary lifestyle that limits performance of activities of daily living (ADL), and aggravates the already significant health and economic consequences of stroke (Liu et al. 2003).

The majority of studies investigating functional recovery after stroke have been conducted in developed countries (Coupar et al. 2012; Verheyden et al. 2008; Page 2006). Only limited literature is available that reports outcomes and recovery patterns of stroke patients living in developing or under-resourced countries such as in Africa (Batcho et al. 2013; Imarhiagbe et al. 2014; Kossi et al. 2016). A 6-month observational cohort study involving 68 stroke subjects from Benin Republic showed that mean improvement in functional recovery was approximately 50% during the first 6 months after stroke (Kossi et al. 2016). These results could be partly explained by the observation that stroke patients in developing countries are generally younger (~60 years of age) compared with stroke patients in

developed countries (> 70 years of age) (Nakayama et al. 1994). The results are very promising and should be strengthened by implementing cost-effective and sociocultural tailored strategies for promoting regular activities in people with stroke in Africa.

1.2.3. Participation restrictions after stroke

“Participation restrictions” is defined in the ICF as problems individuals may experience in involvement in life situations including daily activities and social roles. After one year, many stroke survivors will still experience restrictions in domains related to mobility, housekeeping, and outdoor activities, despite being independent in basic activities of daily living (van der Zee et al. 2013; de Graaf et al. 2017).

Several studies found that after stroke onset, participation improves in the first three to six months, followed by a stable phase (Adamit et al. 2015; Mayo et al. 2002; Rochette et al. 2007). Several factors have been found to contribute to participation restrictions after stroke, including cognitive deficits, (Viscogliosi et al. 2011; Corbett et al. 1994) emotional deficits, (Andrenelli et al. 2015; D'Alisa et al. 2005), functional dependency, (Yang et al. 2013; Gadidi et al. 2011), and increasing age (Andrenelli et al. 2015; Desrosiers et al. 2006).

The involvement in life situations (participation) and interactions with others in a given sociocultural environment may constitute a factor of social

reintegration after long-term disability such as stroke (Barclay et al. 2015; Plow et al. 2013). Therefore, social and cultural environments remain important factors throughout the rehabilitation process after a stroke. A central issue is that the nature and complexity of a stroke patient's environments change from one culture to another. 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 (e.g, SATIS-Stroke) (Bouffoulx et al. 2008) or adapted (e.g, Reintegration to Normal Living Index) (Daneski et al. 2003) for use in Europe might not be fully useful as a practical tool in Africa until its applicability has been checked (Lundgren-Nilsson et al. 2005; Sogbossi et al. 2014). Based on articles published after 2001, a recent systematic review (unpublished paper, (Kossi, Amanzonwe, et al. 2017a)) found 6 existing ICF-based tools for the measurement of participation in adult stroke survivors. These tools are: the WHODAS II in stroke (Kucukdeveci et al. 2013), the London Handicap Scale (Park et al. 2014), the Community Integration Questionnaire (Dalemans et al. 2010; Liu et al. 2014), the SATIS-Stroke (Bouffoulx et al. 2008), the Reintegration to Normal Living

Index (Daneski et al. 2003), and the Participation Enfranchisement (Heinemann et al. 2011). After a qualitative analysis of these scales content in regard to the African sociocultural context, authors concluded that these tools can not be rigorously applicable in Africa without prior analysis of their functioning. Hence the need to develop and validate African sociocultural tailored scales for the measurement of participation.

1.2.4. Quality of life versus participation

The term "quality of life" (QoL) was introduced for the first time in everyday language in US in the years after the Second World War to describe the effect of material wealth (car, home, food) on people's life. Gradually, the term has been expanded to encompass many other areas such as economics, health, and well-being (Carr et al. 1996). The QoL has not been classified in the ICF probably because of its complexity and its multidimensionality. Indeed, there is no international consensual definition of QoL as it is affected by health (health-related QoL). Definitions range from those with a holistic emphasis on the social, emotional, and physical well-being after treatment (Greer 1984) to those that describe QoL as the impact of a person's health on his or her ability to lead a fulfilling life (Anderson et al. 1996; Bullinger et al. 1993). According to the WHO, the QoL can be defined as "individuals' perception of their position in life in the

context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (Whoqol 1993, 1995).

Although there is no consensual definition of QoL, there is considerable agreement among researchers about some of the characteristics of the QoL construct. First is the recognition that QoL is subjective (Gerin et al. 1992; Patrick et al. 1990; Crang et al. 2008). A second area of consensus is the multi-dimensional nature of QoL (Lindstrom 1992; Schipper 1990; O'Boyle 1992). At minimum, QoL instruments include the following dimensions: physical, psychological and social (individuals' perception of the interpersonal relationships and social roles in their life) (Whoqol 1995). Some QoL measures include further dimensions like environment, spirituality/religion, and personal beliefs (Van Son et al. 2017; Vincent-Onabajo, Owolabi, et al. 2014). As describe above, participation is defined as an individual's involvement in life situations and encompasses 9 domains. There is a broad consensus about the definition of participation, although some authors believe that it is a multidimensional concept. Nevertheless, it is important to notice that the notion of multidimensionality is very relative because it depends mainly on the level of precision.

1.3. Outcome measures in rehabilitation

An outcome measure is defined as a measurement tool (e.g., an instrument, a questionnaire or a rating form) used to evaluate the status or

to document changes in one or more patient's characteristics over time (Cole et al. 1995). The purposes of an outcome measure are to identify the ability at baseline, to document progress, to measure change and finally to improve clinical decision-making about the patient and the rehabilitation program. The use of outcome measures in rehabilitation care is also to enable clinical quality management (Cole et al. 1995). Before a health status measurement instrument can be used in research or clinical practice, its measurement properties, i.e. validity, reliability, and responsiveness, should be assessed and considered adequate (Newton 2012; Mokkink, Terwee, et al. 2010a).

Validity, as described in the literature, has changed over time to become a broad and rather complex issue (Borsboom et al. 2004; Penta et al. 2005a; Newton 2012). According to Borsboom and Mellenbergh, a test is valid for measuring an attribute if the attribute exists and if variations in the attribute causally produce variations in the measurement outcomes (Borsboom et al. 2004). They based their argument in the fact that if something does not exist, then one cannot measure it; and if it exists but does not causally produce variations in the outcomes of the measurement procedure, then one is either measuring nothing at all or something different altogether. According to the Standard for Educational and Psychological Testing (SEPT), "validity refers to the degree to which evidence and theory support

the interpretations of test scores” (Newton 2012). When test scores are used or interpreted in more than one way, each intended interpretation must be validated. Therefore, validity should be seen as a property of an interpretation we make of a test score instead of a property of the test itself. In 2010, the COSMIN checklist (COnsensus-based Standards for the selection of health status Measurement INstruments) was developed in an international Delphi study to evaluate the methodological quality of studies on measurement properties of health-related patient reported outcomes (HR-PROs)(Mokkink, Terwee, et al. 2010a). The topics discussed in the study were content validity, criterion validity, construct validity, internal consistency, measurement error, reliability, and responsiveness. Content validity was defined as the degree to which the content of a HR-PRO instrument is an adequate reflection of the construct to be measured (Mokkink, Terwee, et al. 2010b). The Delphi panel agreed that content validity should be assessed by making a judgment about the relevance and the comprehensiveness of the items. The relevance of the items should be assessed by judging whether the items are relevant for the construct to be measured, for the study population, and for the purpose of the HR-PRO (Mokkink, Terwee, Knol, et al. 2010). Construct validity is defined as the degree to which the scores of an HR-PRO instrument are consistent with hypotheses (for instance with regard to internal relationships, relationships to scores of other instruments, or differences between relevant groups)

based on the assumption that the HR-PRO instrument validly measures the construct to be measured (Mokkink, Terwee, et al. 2010b).

1.4. Measurement framework of this thesis: the Rasch Model

Measurement requires an abstraction or construct which represents the attribute being measured. Indeed, when measuring, for example, the length of an object, we refer to an abstract or latent continuum represented on the measurement instrument being used. The measure is generally conceived as a point along the abstract measurement scale, which is implemented by the instrument. By analogy, to measure participation, we should refer to an abstract or latent continuum of participation. Measuring the participation of an individual should thus be equivalent to determining the position of that individual along an underlying scale of participation. A line conceptualized from “less participating” to “more participating” should represent a gradient and increasing levels of participation could be materialized by individuals of increasing participation. In general, a scale requires thus a manifest order and should focus on one attribute at a time (unidimensionality).

To measure a latent variable (i.e. variables which are not directly observable), such as the participation of an individual, it is necessary to use a questionnaire with either categorical rating or magnitude estimation methods. For instance, to measure the participation of an individual through categorical rating, subjects’ perception of participation can be rated using a

dichotomous response format, e.g. “not at all” (scored 0) and “strongly” (scored 1), or a polytomous response format, e.g. “not at all” (scored 0), “weakly” (scored 1) and “strongly” (scored 2). Usually, the response scores will be summed together into a total score. Such measurement provides thus ordinal scores without a unit. Ordinal scores come, however, with severe shortcomings, precluding the objective measurement¹ of a variable (Tesio et al. 2007; Mellers 1983; Penta et al. 2005a). Firstly, ordinal scores are not necessarily linear (Bond et al. 2001). For instance, equal distances (e.g. from 0 to 1 and from 1 to 2) may not reflect the same amount of the measured variable. Secondly, ordinal scores are not necessarily unidimensional (i.e. the score reflects not only one attribute of the subject) (Bond et al. 2001). As a result, adding individual ordinal scores may result in a total score that is meaningless (Wright et al. 1989). Thirdly, ordinal scores are not necessarily objective (Bond et al. 2001). For example, a given subject taking an easy test will get a high score, while he/she will get a lower score when taking a more difficult test of the same kind. Hence, the difficulty of the test needs to be extracted from the score before appraising the subject’s measure (Hobart et al. 2009). Lastly, ordinal scores are not necessarily invariant under changes of the populations employed to

¹ The Institute for Objective Measurement (IOM, www.Rasch.org) defines objective measurement as “the repetition of a unit amount that maintains its size, within an allowable range of error, no matter which instrument, intended to measure the variable of interest, is used and no matter who or what relevant person or thing is measured”.

generate the data (e.g. systematic differences between males/females) (Bond et al. 2001).

The Rasch model can be used to establish linear, unidimensional, and invariant scales from ordinal scores by locating subjects and items (i.e. perceived participation) along a single underlying scale (Rasch 1980; Bond et al. 2001; Wright et al. 1989). Indeed, the formulation of the Rasch model is articulated around the requirements of unidimensionality and invariance. The model requires unidimensionality in the data since only one trait of the subject and one trait of the item are modelled to determine the probability of the observed response when any subject answers any item. For polytomous response scales, an additional parameter is used to model the threshold between successive response categories. The model also requires invariance in the subject/item interaction since the probability of observing a given response category is modelled to vary neither with person factors (e.g. age, gender, occupation) other than the one being measured nor with item factors (e.g. mobility, self-care, relationships and interactions, community, civic and social life) other than the one being measured. Both of these qualities are required for any fundamental measurement (Rasch 1980; Merbitz et al. 1989). For instance, the length of an object can be measured with a meter stick, which is supposed to provide results that are independent of the object's color, shape or temperature.

When comparing the measure of two objects obtained with the same ruler the measures are not supposed to depend on objects properties (e.g. shape and color) other than the length being measured. Furthermore, the Rasch model requires an independence of the object's measure relative to the instrument (i.e. the items) which was used to obtain the measure. Provided that all items fit with the same latent scale the resulting measure should not depend on the particular items that were used to obtain it. This may be illustrated by the measurement of an object's length, which can be equally measured with a ruler, a meter tape or a folding meter as all these instruments refer to the same underlying definition of the meter (the unit of the latent scale underlying all length instruments).

Unlike the scores obtained by any traditional rating method, the Rasch model provides measures that are expressed on a linear scale. The unit on the measurement scale is the logit (which stands for log-odds-unit) computed as the logarithm of the odds for subject “*n*” to pass threshold “*k*” on item “*i*”:

$$\ln \left(\frac{P_{nik}}{P_{nik-1}} \right) = \beta_n - \delta_i - \tau_k$$

where β_n is the subject proficiency (i.e. “participation level”), δ_i is the item difficulty, τ_k is the threshold between response categories *k* and *k*-1, P_{nik} is the probability for subject “*n*” to select category “*k*” for item “*i*” and P_{nik-1} is

the probability for subject “n” to select category “k-1” for item “i”. The resulting measurement scale is linear since an increase of the subject location by one logit corresponds to an increase in the odds for the subject to perceive his/her participation as “strongly” rather than “weakly” by a constant factor of 2.71 (*i.e.* the Neperian constant).(Wright et al. 1982a) Just like one centimeter represents the same amount of length throughout the range of any length measurement instrument.

1.5. Purposes of this thesis

The general focus of this thesis is to contribute in the management of stroke care in Africa. To achieve this general purpose we set 4 specific goals that will be addressed in 4 chapters as described hereafter.

In Chapter I we describe the functional recovery in a sample of 68 stroke survivors from the Republic of Benin. Participants were followed up over 6 months and were evaluated at 4 time points: at enrollment, at 1 month, at 3 months and 6 months. Overall, results shown that participants improved their activity level up to 50% at 6 months. This chapter is presented as published in the *Journal of Rehabilitation Medicine*.

In Chapter II we present the development and investigation of initial psychometric properties of the Participation Measurement Scale (PM-Scale), a new tool for the measurement of participation in Africa. Two hundred seven-six participants suffering from stroke were recruited in Benin

and in Burundi. A research questionnaire of 100 items have been administrated to the sample. Data were analyzed with the RUMM2030 software, and a final scale of 22 items covering the 9 domains of the ICF was constructed. Individual item and person fit to Rasch model were good. Internal consistency, test-retest reliability, and invariance of items hierarchy and individuals' location were both good. Results of this chapter are presented as published in the *Archives of Physical Medicine and Rehabilitation*.

In Chapter III we investigate the responsiveness of the PM-Scale. A sample of 64 participants with stroke has been followed-up over 6 months with 3 evaluations time points: at 1 month, at 3 months and 6 at months. Different approaches (global, group, and individual) as well as different statistical indices (ANOVA, Effect size, and t-score) have been used to check the ability of the PMS to detect changes over time. Results showed that the PM-Scale is very sensitive to change and can be used to monitor participation after stroke in African countries. These results are presented as under review in the *Archives of Physical Medicine and Rehabilitation*.

In Chapter IV we analyze the relationships between impairments, activity limitations and participation restrictions after stroke in Benin. We recruited a sample of 64 participants with stroke in 3 outpatient rehabilitation centers and followed them up to 6 months. They were evaluated at 3 time points: 1

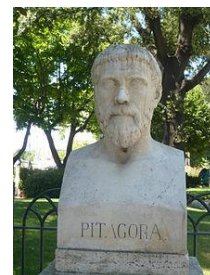
month, 3 months and 6 months. ANOVA, correlation indices, and multiple linear regressions were used to investigate the relationships between the three dimensions of ICF and to predict participation after stroke. Our findings show that during the first 6 months after stroke, the ACTIVLIM-Stroke measure is the best predictor of participation, explaining at least 40% of the variance of the PM-Scale measures. This chapter is presented as an article in preparation.

Chapter I

Functional recovery after stroke in Benin: A 6-month follow-up study.

« Choisis toujours le chemin qui semble le meilleur même s'il paraît plus difficile:
l'habitude le rendra bientôt agréable».

Pythagore



2.1. Abstract

Background: Stroke is a major public health problem in developing countries. However, few studies have quantified the functional recovery of stroke patients in sub-Saharan Africa. This study examined the functional recovery of stroke patients in the Republic of Benin.

Methods: A total of 68 patients with acute stroke were recruited from hospitals and health centres in Benin. Patients were evaluated at enrolment and 1, 3 and 6 months post-stroke. The ACTIVLIM-Stroke scale, Barthel Index, and modified Rankin Scale were used to assess activity limitations, functional autonomy, and overall level of disability, respectively.

Results: Over the 6-month follow-up period, 18 patients died and 9 dropped out. Overall, the 3 measures highlighted progressive and significant functional recovery during the first 6 months. At enrolment, the mean score on ACTIVLIM-Stroke was 16% (standard deviation (SD) 9), indicating that patients were almost totally dependent and unable to perform most activities of daily living. At 6 months, the mean score for activity limitation reached 67% (SD 15) and most patients were able to perform some basic tasks easily. Patients had difficulty with tasks requiring

² Published in Journal of Rehabilitation Medicine (J Rehabil Med, 48: 671-75).

walking and remained unable to perform certain activities requiring manual dexterity.

Conclusion: The study sample showed significant functional recovery (~50%) during the first 6 months post-stroke. We recommend the integration of group-based brisk walking into a cost-effective rehabilitation programme as a suitable way to increase functional recovery of chronic stroke patients in sub-Saharan Africa after hospital discharge.

Key words: stroke; neuro-rehabilitation; functional recovery.

2.2. Introduction

In its 1989 report, the World Health Organization (WHO) recognized stroke as a major cause of death and disability worldwide (WHO 1989). Recent global estimates found that stroke ranked as the second most common cause of death, with 5.9 million stroke-related deaths in 2010 (Feigin et al. 2014). In sub-Saharan Africa the estimated pooled prevalence of stroke is 3.5 per 1,000 populations, and this statistic is predicted to increase annually by 12% (Ezejimofor et al. 2016). Risk of death after stroke is much higher in low-income compared with high-income countries (Owolabi 2011). Possible explanations for this observation have been proposed. For instance, low-income countries often lack political and operational programmes for the prevention and monitoring of cardiovascular risk factors, such as high blood pressure, in at-risk populations. Developing countries also lack qualified and motivated staff or adequate technical facilities for the management of large numbers of stroke cases (Adoukonou et al. 2010). Several studies have concluded that stroke concerns relatively younger populations in developing compared with developed countries (Adoukonou et al. 2010; Nakayama et al. 1994; Saunders 2004; Walker et al. 2003). In particular, stroke occurs 10–15 years earlier in African populations compared with stroke populations in developed countries (Adoukonou et al. 2010; Nakayama et al. 1994; Saunders 2004; Walker et

al. 2003). Stroke in younger populations leads to a greater loss of potential years of life and huge economic and social burden.(Walker et al. 2003) Early occurrence of stroke in African communities can be explained by a higher prevalence of exposure to risk factors, such as lack of regular exercise, poorly controlled hypertension, consumption of fats and alcohol, and HIV/AIDS (Saunders 2004). Ethnic predisposition also plays a role; although stroke itself is not hereditary, important risk factors for stroke (e.g. atherosclerosis and hypertension) are hereditary. Higher prevalence rates of hypertension have been observed in black African communities living in Africa or Western countries (Saunders 2004). A contemporary hypothesis is that black Africans are genetically predisposed to hypertension, with environmental factors playing an aggravating role. Patients in African countries have limited access to rehabilitation services. Furthermore, there is a dearth of high-quality published studies that adequately quantify functional recovery of stroke patients in sub-Saharan Africa. To our knowledge, no prospective longitudinal research has been conducted to measure outcomes and functional recovery of stroke patients in sub-Saharan Africa over a long period. Therefore, this study aimed to investigate the functional recovery of stroke patients in the Republic of Benin over a 6-month follow-up period.

2.3. Methods

2.3.1. Study design and enrolment

This is a 6-month observational cohort study involving 68 participants. The study received approval from the ethics committee of the Université catholique de Louvain in Belgium and the local ethics committees of medical faculties in Cotonou and Parakou, Republic of Benin. Patients signified their agreement to participate by signing a consent form. Patients were recruited from the records of different hospitals and health centres in Benin. Patients were followed for 6 months after stroke and evaluated 4 times: at enrolment (t0), 1 month post-stroke (t1), 3 months post-stroke (t2) and 6 months post-stroke (t3).

2.3.2. Assessment tools

Participants were assessed with 4 tools:

- A general questionnaire: administered at admission to determine demographics (e.g. socio-professional status) and medical history (e.g. cardiovascular risk factors before stroke onset).
- ACTIVLIM-Stroke (Batcho et al. 2012): a 20-item self-report instrument validated in populations in Benin and Belgium. Built on the Rasch model, ACTIVLIM-Stroke is designed to evaluate activity limitations among adult post-stroke patients. Answers to items are provided through a 3-level format ("impossible", "difficult", and "easy"). The psychometric properties of

this questionnaire motivated our choice of the instrument as the main tool to assess functional outcome in our sample.

- Barthel Index (BI) (Mahoney et al. 1965): one of the most frequently used ordinal generic scales to assess a patient's functional independence in daily life. The total score ranges from 0 to 100, with higher scores indicating better functional status.
- Modified Rankin Scale (mRS) (Rankin 1957): a generic ordinal clinician-rated scale that categorizes severity of disability on the basis of observation. Patients are rated on 7 levels, from 0 ("no symptoms at all") to 6 ("dead"). An increasing mRS score indicates worsening status.

2.3.3. Inclusion criteria

The following conditions were verified before a patient was enrolled: age at least 18 years, diagnosed with acute stroke (enrolled < 30 days from stroke onset), consulted by a neurologist, and no post-stroke cognitive impairment (Mini-Mental State Examination, score ≥ 24).

2.3.4. Data analysis

Data were analyzed with the SPSS software package, version 16. Descriptive statistics were used to describe sample characteristics. One-way repeated analysis of variance (RM-ANOVA) was used to compare ACTIVLIM-Stroke scores obtained at different evaluation times. Post-hoc analyses with Bonferroni adjustment were performed to investigate the

specific differences of scores between t0, t1, t2 and t3. Friedman's non-parametric statistical test was used to compare the results for successive measurements of BI and mRS.

2.4. Results

A total of 76 eligible patients were identified. At enrolment, 2 declined to participate, and 6 did not meet inclusion criteria (i.e. MMSE score < 24); therefore, 68 participants were included in the sample at enrolment (Fig. 1). After 1 month post-stroke, 12 deaths were reported, and 5 patients could not be contacted, leaving a sample of 51 patients. After 3 months, 5 additional deaths were reported, and 4 patients could not be contacted. After 6 months, 41 survivors and 1 death were registered. The final totals were: 26.5% died, 13.2% dropped out and 60.3% were fully followed up to 6 months.

2.4.1. Sample characteristics

The mean age of total sample at enrolment (68 patients) was 60±9 years, with 52% of the sample being men. Most participants (68%) were married or living with a partner. Almost half of participants (46%) were self-employed (independent), and over one third (36%) had never attended school. Stroke type was ischemic in 47%, intraparenchymal haemorrhage in 27%, and undetermined in 26% of the sample. In 56% of cases, stroke lesions were located in the right hemisphere (Table 1). Regarding

cardiovascular risk factors, three quarters of patients had been diagnosed with hypertension before stroke onset. The remaining one-quarter of patients did not know their hypertension status before stroke onset. More than half of participants (68%) were unaware of their blood cholesterol levels before stroke onset. Over 90% of participants were at least 50 years old (Table 2). All participants were admitted to a hospital or health center. The baseline values on the assessment tools were similar ($p > 0.5$) between survivors and patients dropping out and dying. The mean duration of hospitalization of our sample was 22 ± 21 days. The percentages of patients receiving training after the stroke were respectively 38% at enrolment, 55% after 1 month (t1), 24% after 3 months (t2) and 39% after 6 months (t3). The training consisted in classical physical therapy sessions of 45 to 60 minutes 3 to 5 times a week during the first 3 months and 2 times a week after three months.

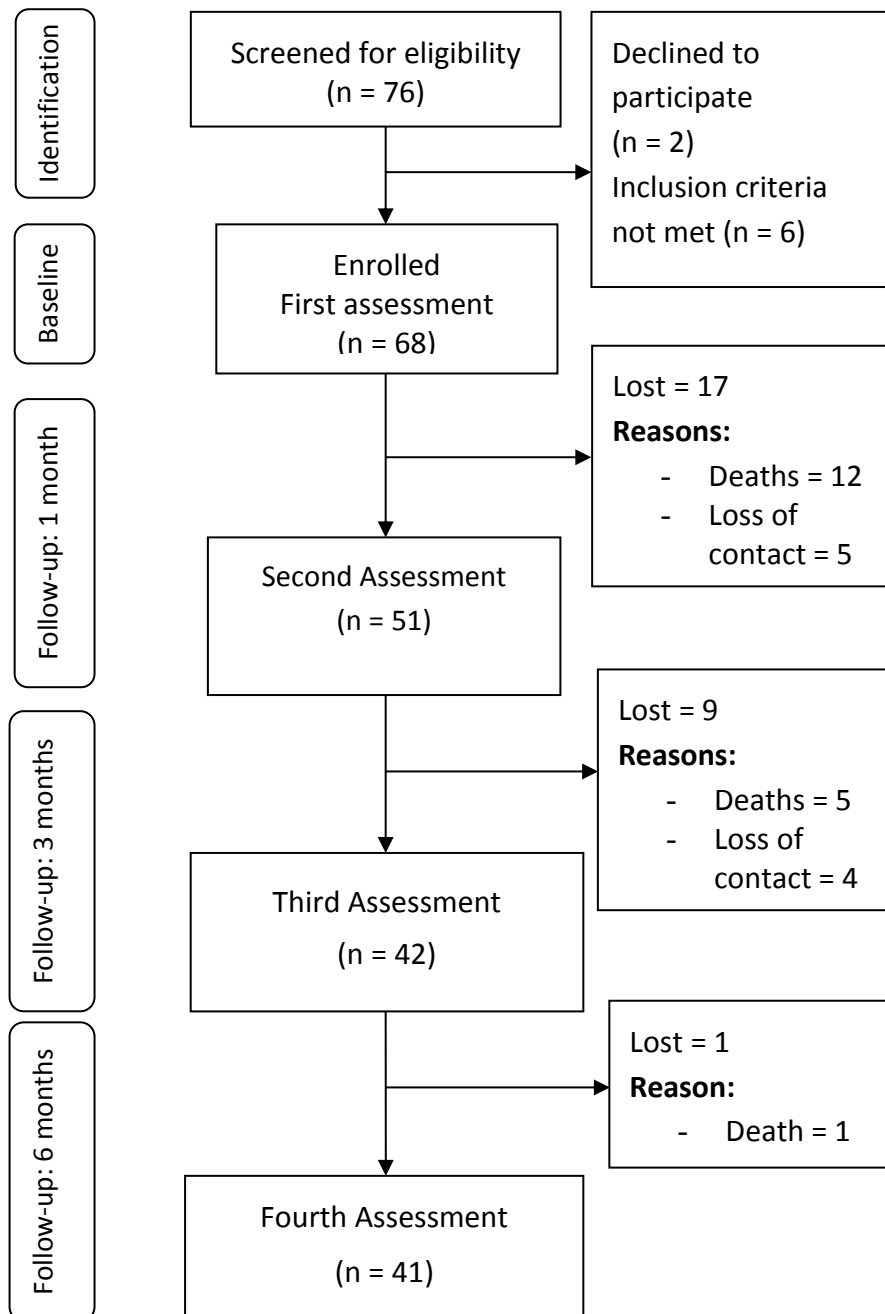


Figure 2 : Flow chart of enrollment

Table 1. Socio-demographic and epidemiological characteristics of the sample

Characteristics	n (%)
Sex	
Male	35 (52)
Female	33 (48)
Marital status	
Cohabitation with partner	46 (68)
Divorced, single	2 (3)
Widower	20 (29)
Professional status	
Employee	18 (27)
Independent	32 (46)
Retired	18 (27)
Level of education	
Did never attend school	25 (36)
Primary	17 (25)
Secondary	16 (24)
Superior, advanced	10 (15)
Social security	
Health insurance	79 (69)
Without health insurance	21 (31)
Type of stroke	
Ischemic	33 (47)
Haemorrhagic	18 (27)
Undetermined	17 (26)
Location of stroke	
Cortical or hemispheric	28 (41)
Capsulo-lenticular (deep location)	30 (44)
Multiple location	10 (15)
Side of cerebral hemisphere injured	
Left	30 (44)
Right	38 (56)

Table 2. Cardiovascular risk factors at enrolment (n=68)

Factors	Present (%)	Absent (%)	Unknown (%)
Age $\geq$ 50 years	91	9	-
Hypertension	75	2	23
Diabetes	13	63	24
Hypercholesterolemia	3	29	68
Smoking	4	96	-
Alcohol	19	81	-
History of stroke	15	85	-

2.4.2. Functional recovery

Table 3 presents the ACTIVLIM-Stroke, BI, and mRS scores. The 3 functional measures highlighted progressive and significant functional recovery during the first 6 months after stroke, although the mRS did not show improvement in scores between enrolment and 1 month. Fig. 2 depicts the functional recovery of our sample at the 4 evaluation times using the ACTIVLIM-Stroke scale. The top panel shows the patients mean functional ability at the 4 times. The bottom panel illustrates the relationship between the ordinal total score and linear measures (in %) according to the calibration of the scale by Batcho and colleagues (Batcho et al. 2012). The middle panel shows the expected response to a given item as a function of patient functional ability.

To understand the functional recovery of our sample, we will describe in detail the mean scores measured at the 4 evaluation times (Fig. 2 and Table 3).

- At enrolment (t0), the mean score was 16% (SD 9), indicating that patients were unable to perform most activities of daily living (ADL). Patients were mostly bedridden and almost totally dependent.
- After 1 month (t1), we observed a slight, but significant, increase (improvement) in the mean ACTIVLIM-Stroke score, to 25% (SD 22) ($p < .01$). Patients began to be able to perform some ADLs with difficulty, including “opening a door”, “brushing one’s teeth”, and “putting a key in a lock”.
- After 3 months (t2), functional recovery had increased significantly. Mean score was 43% (SD 25) ($p < .001$). Patients began to be able to perform, with difficulty, ADLs requiring motor skills, such as “getting up from a chair”, “taking off a t-shirt”, and “getting out of a car”.
- After 6 months (t3), patients continued to recover; the mean score for activity limitation reached 67% (SD 15) ($p < .001$). Most patients were able to perform some basic tasks easily, including “brushing one’s teeth” and “using the toilet”. They had difficulty in performing activities involving walking, such as “walking more than 1 km” and “walking upstairs”. They remained unable to “carry a heavy load” or to perform some activities requiring manual dexterity, such as “tying one’s laces”.

In summary, Fig. 2 demonstrates that our sample of 41 patients improved their functional recovery by approximately 50% during the 6 months post-stroke.

Table 3. Evolution of functional recovery for the entire sample

Scale	t₀ (n = 68)	t₁ (n = 51)	t₂ (n = 42)	t₃ (n = 41)	Overall dif.	t₀vs t₁	t₁vs t₂	t₂vs t₃
					p-value	Post-hoc		
ACTIVLIM-Stroke , %, mean ± SD	16±9	25±22	43±25	67±15	< .001	< .01	< .001	< .001
BI , médiane, [P25 ; P75]	20 [0 - 85]	40 [10 - 95]	65 [50 - 100]	75 [65 - 100]	< .001	< .01	< .001	< .001
mRS , médiane, [P25 ; P75]	5 [4 - 5]	5 [4 - 5]	4 [3 - 5]	3 [3 - 5]	.018	.53	.032	.041

SD: standard deviation; mRS: Modified Rankin Scale; P: percentile; dif: differences; BI: Barthel Index; mRS: modified Rankin Scale.

2.4.3. Individual consideration of the functional recovery

The ACTIVLIM-Stroke scale provides measure with standard errors, enabling investigation of individual-level changes. Table IV reports the status of patients between consecutive evaluations, according to the ACTIVLIM-Stroke scale. Percentages are based on the sample size at each time-point. The results demonstrated that most patients improved their functional status, particularly from 1 to 6 months post-stroke.

Table 4. Functional recovery across 6 months post-stroke using the ACTIVLIM-Stroke scale

Patient's status	t ₀ vs t ₁ (N = 68)	t ₁ vs t ₂ (N = 51)	t ₂ vs t ₃ (N = 42)
Improvement, n (%)	36 (54)	39 (76)	40 (96)
Stable, n (%)	15 (21)	3 (6)	-
Degradation, n (%)	1 (1)	-	1 (2)
Deaths, n (%)	12 (17)	5 (10)	1 (2)
Missing data, n (%)	5 (7)	4 (8)	-

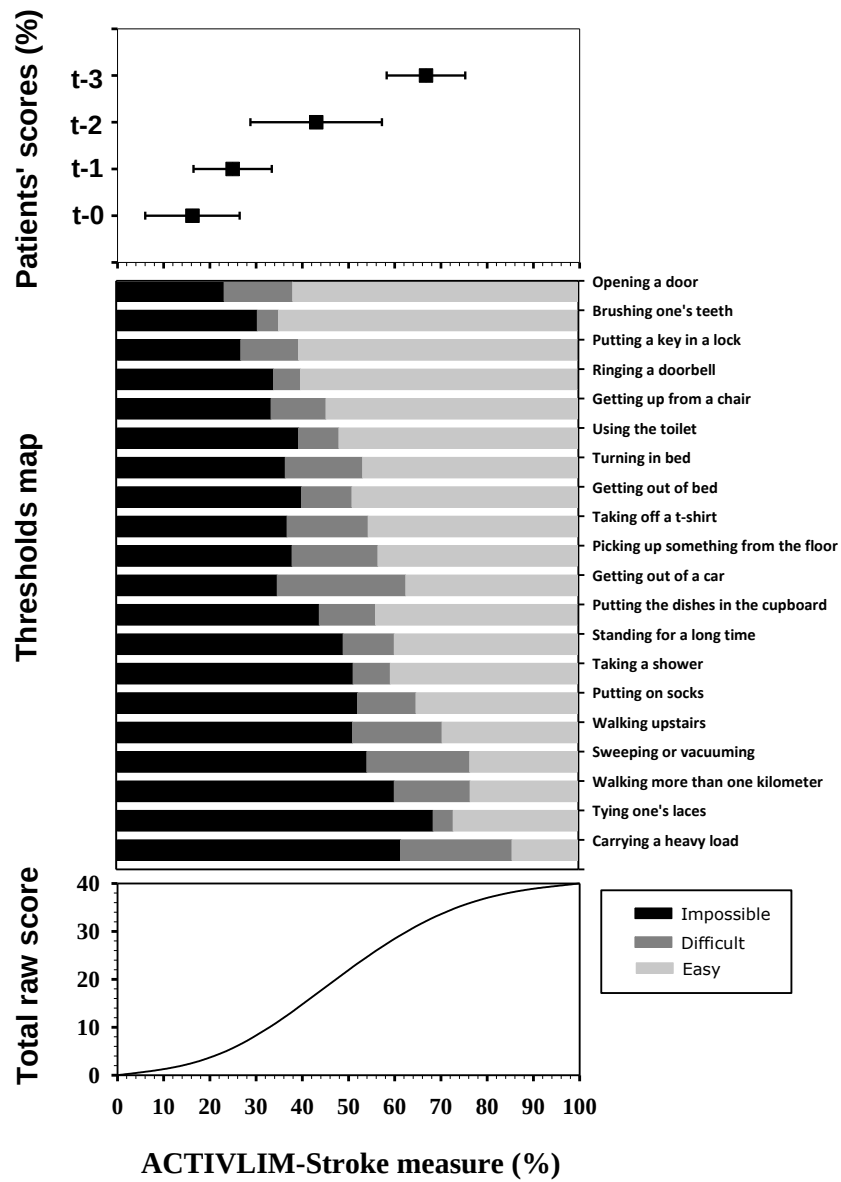


Figure 3. Functional recovery of the sample at the 4 evaluation times (t0, t1, t2, t3) using the ACTIVLIM-Stroke scale.

2.5. Discussion

The purpose of this study was to investigate the functional recovery of stroke patients recruited from different localities in the Republic of Benin, a sub-Saharan Africa country. Global analysis of our sample showed that patients recovered more than 50% of normal functioning during the 6 months after stroke, with the mean ACTIVLIM-Stroke score increasing from 16% (SD 9) at enrolment to 67% (SD 15) at 6 months post-stroke ($p < .001$, Table III). Nevertheless, in clinical trials, change that is meaningful for a group might not be meaningful for individuals (Redelmeier et al. 1990). Fortunately, because the ACTIVLIM-Stroke scale gives measures with standard errors, this instrument allows investigation of individual-level changes. The individual-based analysis indicated that 96% of our participants reported an increase in their ability to perform ADLs after 6 months post-stroke.

These promising results regarding rate of functional recovery can be partly explained by the observation that stroke patients in developing countries are generally younger (~60 years of age) compared with stroke patients in developed countries (> 70 years of age) (Adoukonou et al. 2010; Nakayama et al. 1994; Saunders 2004; Walker et al. 2003). Indeed, in a prospective community-based study of 515 consecutive acute stroke patients, Nakayama and colleagues (Nakayama et al. 1994) reported that

age independently influenced stroke outcomes selectively in ADL-related aspects, but not in neurological aspects. Their results suggest a better compensatory ability in younger stroke patients. Hence, the mean age of our participants (60 years (SD 9)) might explain the observed good functional recovery.

By 6 months, most ADLs had become easy for participants, with the exception of activities demanding walking ability (e.g. “walking more than 1 km”, “walking upstairs”, and “carrying a heavy load”) or manual dexterity (e.g. “tying one’s laces”). Reduction in walking ability is a major devastating outcome of stroke, and its restoration is of great importance to patients and their relatives. Recently, Batcho et al. (Batcho et al. 2013) reported that group-based brisk walking improved body functions and activities in community-dwelling stroke patients. In that study, a 3-month walking programme helped participants to reduce their impairments, improve their balance, and recover their functional autonomy. Thus, regular ground walking is a low-cost intervention that has the potential to stimulate functional recovery in chronic stroke survivors. This finding contributes to increasing evidence that exercise after stroke has many benefits, and that chronic stroke survivors may be encouraged to be active. We recommend integrating group-based brisk walking in community-based rehabilitation (CBR) efforts (Mauro et al. 2014). Promoted by WHO, CBR is a multi-

sectorial strategy that focuses on enhancing the quality of life of people with disabilities and their families; its implementation requires combined efforts of people with disabilities, their families, and their communities. As the prevalence of disability in low-income countries increases, rehabilitation programmes will become increasingly necessary (Ezejimofor et al. 2016). Therefore, the implementation of evidence-based CBR in addition to models of rehabilitation from high-income countries may help to address the growing needs of rehabilitation programmes in the sub-Saharan Africa environment.

This study has been focused on the estimation of the functional recovery in a sample of Beninese stroke patients. According to the International Classification of Functioning, Disability and Health (ICF), disability is not just an anatomical and functional ability issue, but also involves the individual's involvement in real-life situations. Thus, we suggest that further investigations fill this gap by taking into account the participation dimension. Another limitation of our study is the sample size, meaning that our findings related to 68 patients cannot be generalized to the whole stroke population of sub-Saharan Africa.

2.6. Conclusion

Our sample from the Republic of Benin showed mean improvement in functional recovery of approximately 50% during the 6 months after stroke.

This good functional recovery may be explained by the young age of our sample (~60 years). We suggest the integration of group-based brisk walking in CBR programmes as an effective and economical approach to increase functional recovery in the chronic stroke population of sub-Saharan Africa.

Chapter II

Measuring Participation after Stroke in Africa: Development of the Participation Measurement Scale.

« Observations are always ordinal; measurements, however, must be interval ».

Benjamin Drake Wright



Measuring Participation after Stroke in Africa: Development of the Participation Measurement Scale.³

2.1. Abstract

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

Design: Observational study and questionnaire development.

Setting: Outpatient Rehabilitation centers.

Participants: Stroke patients (N = 276); mean age $\pm$ standard deviation of 58.5 ± 11.1 years; 57% males.

Intervention: 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 the 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 RUMM2030 software package under unrestricted partial-credit parameterization, a valid,

³ Published in Arch Phys Med Rehabil. doi: 10.1016/j.apmr.2017.10.004.

unidimensional and linear 22-item scale for the measurement of participation was constructed. All 22 items fulfilled the requirements of an objective measurement, namely unidimensionality, category discrimination, invariance, and local response independence. The PM-Scale showed good internal consistency (person separation index = 0.93). The test–retest reliability of item difficulty hierarchy ($r = 0.96$, $p < 0.001$) and patient location ($r = 0.99$, $p < 0.001$) were excellent. This patient-based scale covers all nine ICF domains of participation.

Conclusions: The PM-Scale has good psychometric qualities and provides accurate measures of participation in patients with stroke in Africa.

Keywords: Stroke ■ Participation ■ Scale ■ Africa

2.2. Introduction

Stroke remains a major global health problem (Feigin et al. 2014; Feigin et al. 2015; Krishnamurthi et al. 2013). and its significance is likely to increase in the future due to ongoing demographic changes, including aging of the population and health transitions observed in developing countries (Feigin et al. 2015; Roth et al. 2015). In Africa, the estimated pooled prevalence of stroke is 3.5 per 1,000, with an annual increase of 12.0% (Ezejimofor et al. 2016). Disability following stroke results from complex and dynamic interactions between impairments and contextual barriers, which could hinder individuals' participation in society (Jansen et al. 2012). Participation has been described in the International Classification of Functioning, Disability and Health (ICF) as an individual's involvement in life situations, (ICF. 2001) 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; employment and economic life; and community, social and civic life.

Since the publication of the ICF in 2001, the concept of participation has become central in discussions across rehabilitation science (van der Mei et al. 2007). Much has been written to describe and explore how to measure participation (Bouffoulx et al. 2008; Daneski et al. 2003; Heinemann et al. 2011; Resnik et al. 2009). Several ICF-based tools have been designed,

most notably in the occidental context, to assess participation in stroke patients. These tools include the Community Integration Questionnaire (CIQ), (Dalemans et al. 2010) SATIS-Stroke scale, (Bouffioulx et al. 2008) Reintegration to Normal Living Index, (Daneski et al. 2003) London Handicap Scale, (Park et al. 2014). Participation Enfranchisement, (Heinemann et al. 2011) and WHODAS II in stroke (Kucukdeveci et al. 2013). A recent systematic review examined the performance of existing ICF-based tools in measuring participation in stroke survivors, (Kossi, Amanzonwe, et al. 2017b) and found some limitations to their applicability in the African sociocultural context. These limitations concern the administration procedure which is by mail, by post, or by self-report for some tools (Bouffioulx et al. 2008; Daneski et al. 2003). 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 (55 years and older) can read and write (Smith-Greenaway 2015). Other sociocultural differences across continents are for example the existence and use of public transportation, and 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 very religious, either through Christianity or Islam or Endogenous Religions. Such differences between societies need to be

taken into account when measuring latent variables like participation. Consequently culturally tailored measurement of participation among 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.

2.3. Methods

2.3.1. 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: i) presence of unilateral hemiplegia/paresis subsequent to a stroke that had occurred at least 2 weeks previously, ii) absence of any major cognitive impairment that could prevent response in an face-to-face interview (Community Screening Instrument for Dementia (Prince et al. 2011) score ≥ 7), iii) age ≥ 18 years, and iv) liveing in a community (at home).

The study was approved by the 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.

2.3.2. 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), (Rankin 1957) and the Hospital Anxiety and Depression Scale (HADS) (Zigmond et al. 1983). 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 in order to investigate the test-retest reliability of the *PM-Scale*.

2.3.3. Experimental version of the PM-Scale

Based on the ICF framework and existing participation scales for stroke patients, (Bouffioulx et al. 2008; Dalemans et al. 2010; Daneski et al. 2003; Kucukdeveci et al. 2013; Park et al. 2014; Heinemann et al. 2011) 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 (DeWalt et al. 2007). 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 provide a qualitative analysis of the content of the initial questionnaire identifying items that were not relevant to stroke patients, suggesting relevant items that were missing, and reviewing the reading/comprehension level of the questionnaire. No new item was proposed, but seven items were identified as irrelevant and removed. This experimental version of the *PM-Scale*, composed of 100 items, was administered in face-to-face interviews to our sample. This choice was motivated by the great 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 three-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 due to lack of motivation or capability (the two main personal factors that may determine an absence of participation). The category “weakly” 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.

2.3.4. The mRS and HADS

The mRS (Rankin 1957) is a generic ordinal clinician-rated tool that categorizes the severity of disability on the basis of observations. Patients are rated on seven levels ranging from 0 (“no symptom at all”) to 6 (“dead”). Higher mRS scores indicate worse conditions. The HADS (Zigmond et al. 1983) is a generic anxiety and depression scale developed more than 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. HADS and mRS were used to characterize the sample and to investigate Differential Item Functioning (DIF) of the *PM-Scale*.

2.3.5. Data analysis

2.3.5.1. Rasch analysis and item selection strategy

Patients’ responses to the experimental version of the *PM-Scale* were analyzed using the RUMM2030 Rasch analysis package, (Andrich et al. 2012) under 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 (Tennant et al. 2007; Tesio et al. 2007; Wright et al. 1989). In short, Rasch analysis transforms ordinal total raw scores into interval scale measures (Tennant et al. 2007). The model estimates the locations of patients (i.e., participation levels) and the location of items and thresholds (i.e., relative difficulty) on a common underlying unidimensional linear scale of participation (Wright et al. 1982b). 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 (Penta et al. 2005b).

During successive analyses, the following criteria were used to select items. (i) *Missing data*. Items that had a missing response $\geq 20\%$ were considered as irrelevant to patients' life situations. (ii) *Category and threshold discrimination*. For each of the 100 items, the three categories of response defined two consecutive thresholds: one 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 two adjacent categories for an item with a given difficulty. When thresholds are reversed, patients with higher participation levels may choose a lower category than patients with lower participation levels. Reversed thresholds reflect improper discrimination of

response categories. Items with reversed thresholds were deleted. (iii) *Item fit statistics*. Individual item fit was examined by assessing the deviation of observed scores from the model expected scores through fit residual distributions and the chi-squared (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 (Pallant et al. 2007; Tennant et al. 2007). 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. (iv) *Differential item functioning (DIF)*. This measure was used to check the invariance of the scale in terms of six personal factors: sex (females vs. males), time since stroke onset (≤ 6 months [recent] vs. > 6 months [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 (≤ 60 years [median] vs. > 60). Items showing significant DIF for any factor were removed. (v) *Response dependency*. This measure, which links responses to different items once the main underlying trait has been factored out and which might artificially inflate reliability (Marais et al. 2008;

Tennant et al. 2007). Response dependency was investigated by examining the item residuals correlation matrix. When residuals for two items were highly correlated ($r > 0.3$), (Batcho et al. 2012) a patient's response to one item was considered to influence the response to the other item, and one out 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.

2.3.5.2. 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's alpha (Fayers et al. 2007; Tennant et al. 2007) and which indicates the extent to which distinct levels of participation can be distinguished in the sample (Fisher 1992; Wright et al. 2002). To be useful, the scale must enable separation of individuals into at least two strata (Wright 1996). 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.

2.4. Results

2.4.1. 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 5.

2.4.2. Item selection

None of the experimental 100 items of the *PM-Scale* had missing responses $\geq 20\%$, but 31 items showed reversed thresholds and were removed. Of the 69 remaining items, 47 were removed for misfit to the model. The 22 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*.

Table 5. Sample's characteristics

	Mean (SD) [CI _{95%}]	Median (range)
Age, years	59 (11) [57; 60]	57 (18 – 84)
<i>Benin</i>	58 (10) [57; 60]	60 (35 – 82)
<i>Burundi</i>	57 (15) [53; 61]	58 (18 – 84)
Sex		
<i>Male</i>	157 (57%) ‡	
<i>Female</i>	119 (43%) ‡	
Side of hemiparesis		
<i>Right</i>	130 (47%) ‡	
<i>Left</i>	146 (53%) ‡	
Time since stroke, months	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)

SD: Standard Deviation; CI: Confidence Interval; mRS: modified Rankin Scale. ‡ Number (percentage).

2.4.3. Final version of the PM-Scale

Description of the scale

The final 22-item *PM-Scale* demonstrated excellent overall fit for items (mean ± SD, -0.04 ± 1.19) and persons (mean ± SD, -0.21 ± 0.85). Nonsignificant item–trait interaction ($\chi^2 = 80.58$, degrees of freedom = 66, $p = 0.11$) indicated that the hierarchy of item difficulty did not vary across the scale. Table 6 shows estimated item difficulty, associated standard errors (SE), and fit statistics. Items are ordered according to difficulty from the easiest (“understand a gesture of goodbye”, -3.79 logits) to the most

difficult (“occupy a position of responsibility in my religion organization”, 5.02 logits). The data also show that the *PM-Scale* conceptually covered all nine ICF domains of participation.

Figure 4 depicts the structure of the 22-item *PM-Scale* to the level of participation in our sample. The top panel (A) shows the distribution of patients’ locations on the scale (range, –5.73 to 5.41 logits). Only one 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 to “not at all” in the 4 most difficult items (Figure 4, B). The range of measurement of the *PM-Scale* was –6.56 to 6.51 logits i.e. 0 to 100 centiles (Figure 4, C).

Figure 5 presents the DIF plot of the *PM-Scale* as a comparison of the hierarchy of the items difficulty, rated in 6 dichotomous subgroups according to: time since stroke (A), state of depression (B), level of disability (C), sex (D), age (E), and country (F). No significant difference in the hierarchy of the items difficulty was found for these 6 criteria in our sample ($p > 0.05$).

Reliability of the PM-Scale

The *PM-Scale* showed very good reliability ($\text{PSI} = 0.93$) and excellent reproducibility (Figure 6). The item hierarchy (Figure 3, A) was invariant across time ($r = 0.99, p < 0.001$), and patients' locations (Figure 6, B) were consistent over time ($r = 0.96, p < 0.001$).

Table 6: Item calibration and individual item fit statistics of the Participation Measurement Scale (PM-Scale)

Item	Location (logit)	SE [†] (logit)	Fit statistics				ICF [#] participation domain								
			Fit residual	χ ²	D F	χ ² prob	d1	d2	d3	d4	d5	d6	d7	d8	d9
1. Understand a gesture of goodbye	-3.79	0.20	0.20	4.35	3	0.23			*						
2. Clearly understand ideas of others	-3.18	0.17	-0.20	2.89	3	0.41			*						
3. Express my gratitude to someone	-2.47	0.19	-1.57	2.38	3	0.50							*		
4. Perform simple mental arithmetic (e.g., 10 + 10)	-2.15	0.15	2.30	5.65	3	0.13	*								
5. Choose clothing appropriate to the climate	-1.98	0.18	-0.75	0.77	3	0.86					*				
6. Know how to express my disagreement in a proper way	-1.96	0.18	1.23	5.78	3	0.12							*		
7. Go to the hospital for care	-1.39	0.14	0.90	0.77	3	0.86				*					
8. Choose my occupations based on priorities	-1.22	0.14	-0.70	4.80	3	0.19		*							
9. Choose my job based on my physical abilities	-0.97	0.13	-1.23	7.39	3	0.06		*							
10. Have hope in my future	-0.83	0.16	-0.18	3.36	3	0.34		*							
11. Have confidence in myself	-0.77	0.13	1.75	2.68	3	0.44		*							
12. Have a clean physical appearance	-0.36	0.13	1.42	2.29	3	0.51					*				
13. Keep my accounts	0.71	0.12	-0.93	6.56	3	0.09								*	
14. Clearly understand the content of a letter	0.86	0.18	-0.17	3.01	3	0.39			*						
15. Have a balanced and varied diet	0.86	0.14	1.91	6.81	3	0.08					*				
16. Involve myself in the decision making of my entourage	1.50	0.13	-0.85	6.02	3	0.11							*		
17. Help people find a solution to a crisis	1.53	0.13	-0.18	2.06	3	0.56		*							
18. Participate in caring for my children or grandchildren	1.91	0.15	0.74	3.48	3	0.32						*			
19. Speak to an audience	2.02	0.14	-2.00	3.36	3	0.34			*						
20. Participate in religious feasts	2.82	0.15	-0.99	3.02	3	0.39									*
21. Engage myself in a neighborhood association	3.86	0.19	-0.57	1.99	3	0.58									*
22. Occupy a position of responsibility in my religion organization	5.02	0.27	-0.94	1.15	3	0.76									*

[†] SE: Standard Error

[#] International Classification of Functioning, Disability and Health

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.

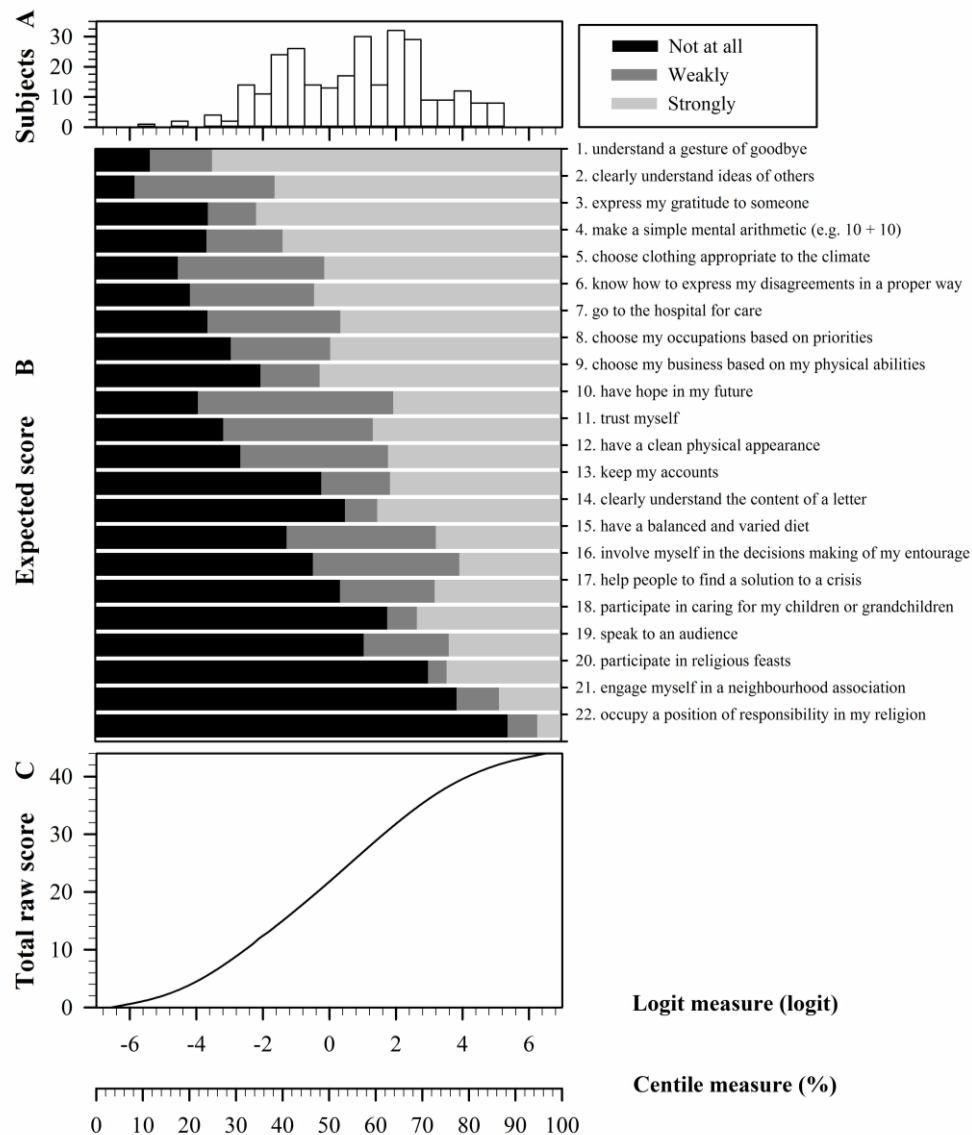


Figure 4: Structure of the PM-Scale presented in 3 panels.

The top panel (A) shows the distribution of patient participation measures. The middle panel (B) shows the threshold map indicating patient's expected response for each item as a function of its participation level. The bottom panel (C) shows the relationship between the ordinal raw scores and the corresponding linear measures.

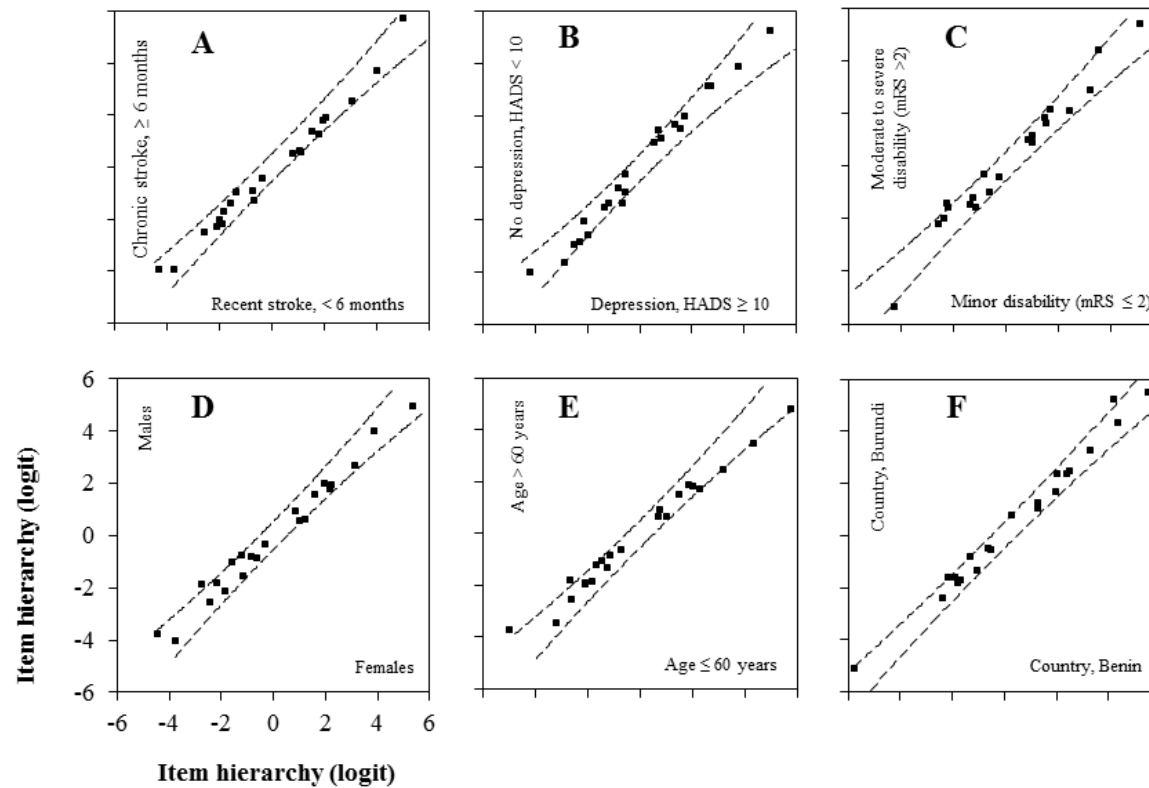


Figure 5: Invariance of the Participation Measurement Scale tested by comparing the hierarchy of items difficulties in dichotomous patients' subgroups according to 6 criteria: time since stroke (A), state of depression (B), level of disability (C), sex (D), age (E), and country (F). For each criterion, 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.

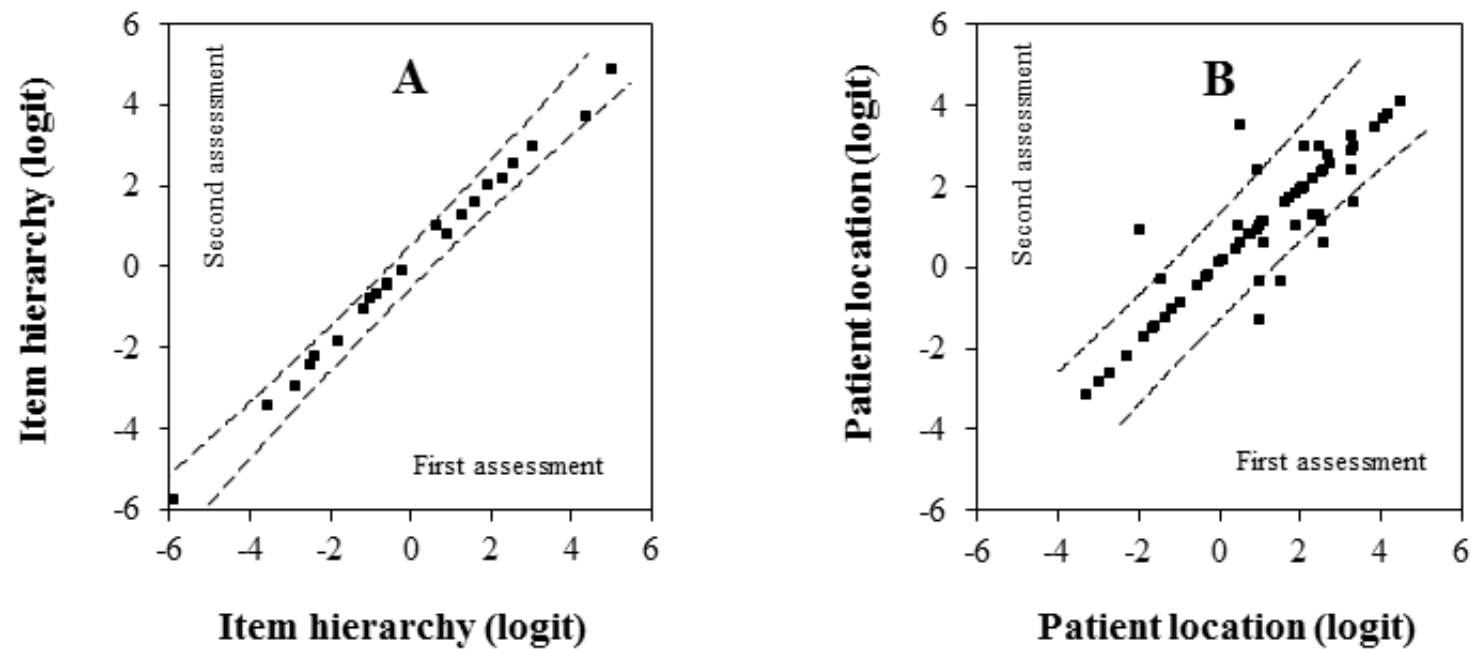


Figure 6: Test-retest reliability of the Participation Measurement Scale illustrated by the reproducibility of the item hierarchy (A) and of the patient location (B) between the first and second assessments. In both panels, the 95% confidence interval of the ideal invariance is indicated by dotted lines.

2.5. 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 stroke patients in Benin and Burundi were analyzed using the Rasch model. From an initial set of 107 items, 7 were removed due to content validity issues and 78 were removed because they did not satisfy to the requirement of an objective measurement, leading to the final version of 22 items scored on a 3-level scale ("not at all," "weakly," and "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 fit 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 0.93, indicating that the scale is reliable, as about 93% of measurement variance was not due to random errors (Marais et al. 2008; Pallant et al. 2007). In clinical practice and research settings, the scale may thus enable distinction of at least five 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 ($r \geq 0.96$, $p < 0.001$). The levels of participation measured in our sample of 276 patients ranged from -5.73 to 4.78 logits, but the minimum and the maximum levels of measurement of the *PM-Scale* were -6.56 to 6.51 logits. Practically, 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 (Panel C, Figure 4) for the transformation of raw scores into interval measures (logits and centiles). However, the conversion is usefull only when no data are missing. For cases of missing responses, online analysis is available (www.rehab-scales.org).

The reference framework for this study was the ICF, which classifies participation into nine 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 nine 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 consistent with those of previous participation measures. For instance, Heinemann and colleagues (Heinemann et al. 2011) also reported that for the participation enfranchisement questionnaire, more difficult items were related to community, social, and civic life (e.g. “I have a say in community decisions”; “I do things to improve my community”; and “I contribute to the general well-being of my community”). Furthermore, Bouffoulx and associates (Bouffoulx et al. 2008) found for the Satis-stroke questionnaire that the item “Participating in spoken exchange of information with your entourage” (communication) is one of the easiest while the item “Choosing appropriate clothes” (self-care) was among the most difficult items. This indicates that overall, the same item difficulty hierarchy is often found in the participation scales. Our findings also suggest that improvement of stroke patients’ participation levels in Africa communities as well as elsewhere requires particular attention to situations demanding community, social, and civic involvement. Beyond 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. In other words, the concept of participation lies beyond the disease-impairment continuum, and several studies have suggested that participation outcomes after stroke are likely to be more relevant to the

patient than impairment itself (de Oliveira et al. 2011). 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, stroke patients 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 (Kossi et al. 2016).

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 relevant to capture the construct of participation in stroke population 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 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 (Vincent-Onabajo et al. 2016).

The evaluation of the effects of stroke on patients' participation in the African population has not yet generated much attention in the literature and in practice. In addition to being a disease-specific and Rasch-built scale with very good psychometric properties, the *PM-Scale* has the advantage of cross-country validity. The 22 *PM-Scale* items describe common situations for community-dwelling stroke patients 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 two areas and could be very 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 further studies.

2.6. 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 three-level scale. The *PM-Scale* is very easy to administer and takes no more than 5 minutes to complete. The *PM-Scale* was administrated in face-to-face interview, allowing the

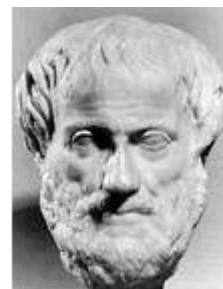
evaluator to provide oral explanations to illiterate patients when needed. However, further studies should analyze the consistency between self-report, proxy-respondent, and face-to-face versions of the *PM-Scale* and the ability of the scale to detect changes over time.

Chapter III

Tracking changes in participation with the Participation Measurement Scale in community-dwelling stroke survivors in Africa.

« Le doute est le commencement de la sagesse ».

Aristote



Tracking changes in participation with the participation measurement scale in community-dwelling stroke survivors in Africa.⁴

3.1. Abstract

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

Design: A six-month observational study with three evaluation time points. Responsiveness of the PM-Scale was investigated at global, group and individual level.

Setting: Rehabilitation centers.

Participants: Participants (N = 64); mean age $\pm$ standard deviation of 56.9 $\pm$ 12.6 years; 70% male.

Intervention: 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 patient.

Results: The PM-Scale detected clinically significant changes in the entire cohort ($p < 0.001$, effect size (ES) = 0.67) and in patient subgroups ($p < 0.001$, $0.25 \leq ES \leq 0.82$). The PM-Scale facilitated the classification of the patients into discriminative groups such as: important improvement ($p <$

⁴ Under revision in Arch Phys Med Rehabil.2017.

0.001, ES = 2.13), moderate improvement ($p < 0.001$, $0.56 \leq ES \leq 0.78$), moderate decrease ($p < 0.001$, ES = 0.67), small decrease ($p = 0.03$, ES = 0.32), and important decrease ($p < 0.001$, ES = 1.45).

Conclusions: The (*PM-Scale*) exhibited good responsiveness and accurately detected clinical changes in stroke subjects' involvement in life situations. These results validate the use of the (*PM-Scale*) for clinical trials and in settings to evaluate the effects of interventions on stroke subjects in Africa. The (*PM-Scale*) also has the potential to guide various stages of health service provisions, including assessment, goal setting, and program planning for individuals and groups in Africa.

Keywords: Stroke ■ Participation Measurement ■ Responsiveness

Introduction

Stroke is a common cause of death and a leading cause of severe long-term disability in both developed and developing countries.(Johnston et al. 2009) In Africa, the prevalence of stroke is among the highest worldwide (Ezejimofor et al. 2016). 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% (Healey et al. 2016; Kossi et al. 2016). Almost 20 years ago the International Classification of Functioning, Disability and Health (ICF) (ICF. 2001) was published and defined participation as an individual's involvement in life situations. 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/her own environment (van der Mei et al. 2007).

Acquiring accurate information regarding participation after stroke is essential since it can serve as a baseline for healthcare planning (Kossi, Amanzonwe, et al. 2017b). It can also help establishing therapeutic guidelines and social interventions (Kossi, Amanzonwe, et al. 2017b). 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 which has recently been proposed to measure participation after stroke in Africa (Kossi, Nindorera, et al. 2017b). In addition to being a disease-specific scale with very good psychometric properties, including reliability, unidimensionality and invariance, the *PM-Scale* is also very easy to administer. It includes 22 items which describe common situations for community-dwelling stroke patients in Africa. It also provides an equal basis for monitoring social participation after stroke in Africa 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 measure 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 (Kossi, Amanzonwe, et al. 2017b; Turner et al. 2013). Therefore, the aim of this study was to investigate the responsiveness of the *PM-Scale* over a period of six months for a cohort of stroke patients.

3.2. Methods

3.2.1. Ethical considerations and inclusion criteria

This 6-month observational cohort study was approved by the Ethic Committee of the Université catholique de Louvain (Belgium) and local ethics committees in Benin (Africa). Participants were recruited from

patients' registers of three rehabilitation centers in Benin. Subjects were eligible for inclusion if they met the following criteria: *i)* unilateral hemiplegia/paresis subsequent to a stroke experienced within 30 days, *ii)* absence of major cognitive impairments that could prevent the patient from responding in a face-to-face interview (Community Screening Instrument for Dementia(Prince et al. 2011) score ≥ 7), *iii)* at least 18 years of age, and *iv)* living in a community (at home). Selected participants signed a consent form and both baseline and follow-up assessments were conducted between November 2015 and April 2016.

3.2.2. Procedure and instruments

During the follow-up process, each patient was evaluated at three time-points: at enrollment (T0), 3-months post-stroke (T1), and 6-months post-stroke (T2). Subjects' participation levels were assessed with the *PM-Scale* which consists of 22 items that refer to daily life situations encountered by stroke survivors in Africa (e.g. "Participate in religious feasts"; "Engage myself in a neighborhood association"; "Occupy a position of responsibility in my religion organization", and so on). The *PM-Scale* has been administrated in face-to-face interview in French language by the first author (K.O.). Participants were asked to report their perceived participation level for each situation as: "not at all" (score = 0), "weakly" (score = 1), or "strongly" (score = 2). As described in the validation study, (Kossi,

Nindorera, et al. 2017b) the *PM-Scale* allows ordinal raw scores to be converted into interval-level measures (in logit and in centiles) on a unidimensional scale. The centiles metric transformation was applied to the *PM-Scale* raw scores in the present study since it is more understandable for clinicians and researchers who are not familiar with the Rasch model. Higher scores indicate higher participation levels.

The modified Rankin Scale (mRS) (Rankin 1957) which is one of the most widely used clinician-reported tool was employed to categorize the overall disability for each participant. The mRS was administrated by a physical therapist working with stroke subjects for more than 10 years. Participants were rated from 0 ('no symptoms at all') to 6 ('dead'). High mRS scores indicate worsening status.

3.2.3. Sample size and data analysis

To determine the sample size needed for the present study, an alpha error of 0,05, a standard deviation (SD) of 0,35 (which represents a conservative figure based on the SD value of 0,20 that was found in the validation study of the *PM-Scale*), minimal difference detection of 0,15, and a power of 0,90 were considered. Thus, 60 patients were determined to be the required sample size. The responsiveness of the *PM-Scale* was investigated at global, group, and individual levels.

At the global level, patients' scores were statistically compared at consecutive assessment time points by using repeated measure analysis of variance (RM-ANOVA) with a Tukey post-hoc automatic correction for multiple comparisons. Normality of the data was checked with the Shapiro-Wilk test while the Levene test was used to investigate the homogeneity of variances. The Effect size (ES) was also used to characterize the magnitude of the internal responsiveness of the PM-Scale. ES was calculated based on the mean change between the average measures of two evaluations divided by the standard deviation of the first evaluation (Liang et al. 1985). ES data were then interpreted by using Cohen's benchmarks, with the magnitude of the changes classified as: non-significant ($ES < .2$), small ($.2 \leq ES < .5$), moderate ($.5 \leq ES < .8$), or large ($ES \geq .8$) (Cohen 1988).

At the group level, responsiveness indices were evaluated in the various subgroups. In the first analysis, two groups were established according to sex. In a second analysis, two groups were established based on the patients' age (≤ 57 years vs. > 57 years). The cut-off age was selected based on the median distribution of the sample age. In a third analysis, two groups were established based on the patients' scores from the mRS at baseline (minor to moderate disability, mRS score ≤ 3 vs. severe disability,

mRS score > 3). ES was used to determine the magnitude of the changes in the three groups.

Finally, to accommodate the consideration that changes that occur in a group may not be meaningful in individuals, (Redelmeier et al. 1990) changes in participation were evaluated at the individual level. For this, t-values, which take into account self-relative measures and their associated errors for a person at two different time points were calculated as follows:(Anselmi et al. 2015)

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

where p_i and p_j represent the patient's participation level at two time points and SE_j and SE_i are the respective associated standard errors of measurement. The calculation of t-values follows a standardized normal distribution and indicates whether the changes observed between two assessment times for a given patient reflect more than a fluctuation of the measuring instrument (Wright et al. 1979). The patients were subsequently divided into five classes according to their t-score significance limits: important improvement ($t \geq 1.96$), improvement ($0 < t < 1.96$), no change ($t = 0$), decrease ($-1.96 < t < 0$), and important decrease ($t \leq -1.96$).

Statistical analyses were performed using JMP software, version Pro 12.

3.3. Results

A total of 91 eligible patients agreed to participate and were enrolled in the study. During the follow-up process, 12 participants dropped out and 15 deaths were reported. Consequently, a total of 64 patients (45 males, 19 females) with a mean age $\pm$ SD of 56.9 ± 12.6 years and time since stroke $\pm$ SD of 24.25 ± 6.1 days were included our study for analysis. This cohort included 30 patients (48.4%) presented with a left paretic side, while 34 patients (51.6%) presented with a right paretic side. Characteristics of the analyzed cohort are listed in Table 7.

Table 7. Participants characteristics at enrollment

	Mean (SD) [CI _{95%}]	Median (range)
Age, years	56.9 (12.6) [53.2; 60.5]	57 (18–84)
≤ 57	48.3 (8.4) [36.3; 46.52]	43.5 (18–56)
> 57	63.1 (10.8) [60; 66.3]	61 (58–84)
Sex		
Male	45 (70.3) [‡]	
Female	19 (29.7) [‡]	
Side of hemiparesis		
Right	34 (51.6) [‡]	
Left	30 (48.4) [‡]	
mRS score at enrollment		4 (2–5)
≤ 3	29 (45.3) [‡]	2 (1–3)
> 3	35 (54.7) [‡]	4 (4–5)

SD: standard deviation; CI: confidence interval; mRS: modified Rankin Scale.

[‡] Number (percentage)

3.3.1. Global-level analysis

Table 8 lists the results obtained from the global evaluation of the *PM-Scale* scores for the present cohort. One-way RM-ANOVA identified significant difference in the data ($F = 31.94$; $p < .001$). The post-hoc test also highlighted significant differences between T0 and T1 ($p < .010$) and between T1 and T2 ($p < .001$). Calculations of ES showed that the entire cohort ($n = 64$) exhibited small ($ES = .33$) changes between T0 and T1 and moderate ($ES = .67$) changes between T1 and T2.

3.3.2. Group-level analysis

According to sex. When mean changes over time was examined for males versus females, no significant difference between the mean scores on the *PM-Scale* was observed between T0 and T1, but a significant difference was found between T1 and T2 (Table 8). The mean change between T1 and T2 was 9% for the males and 4% for the females. This was confirmed with ES values of 0.75 (moderate) and 0.25 (small) that were obtained for the two sexes, respectively.

According to patient age. As shown in Table 8, the mean change in participation was higher among the younger patients than among the older patients between both T0 and T1 (6% vs. 4%, respectively) and T1 and T2 (9% vs. 6%, respectively). This was confirmed by calculations of ES where the changes detected were moderate for the younger patients *versus* small

for the older patients between T0 and T1. Between T1 and T2, the changes detected by ES were large and small for the two age groups, respectively.

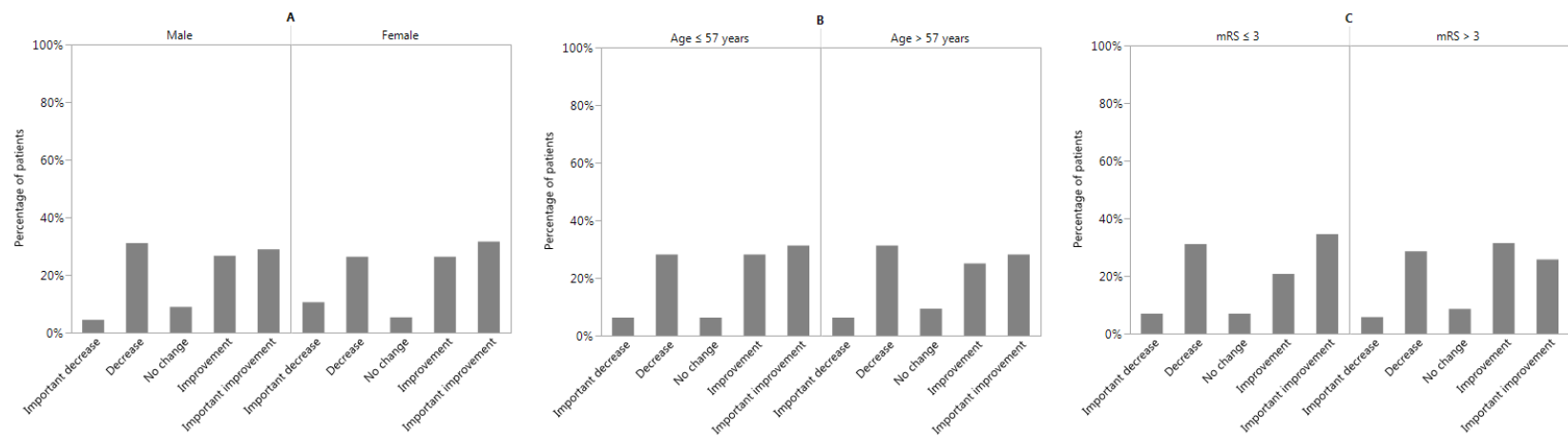


Figure 7. Percentage of participants in each t-value category between T0 and T1

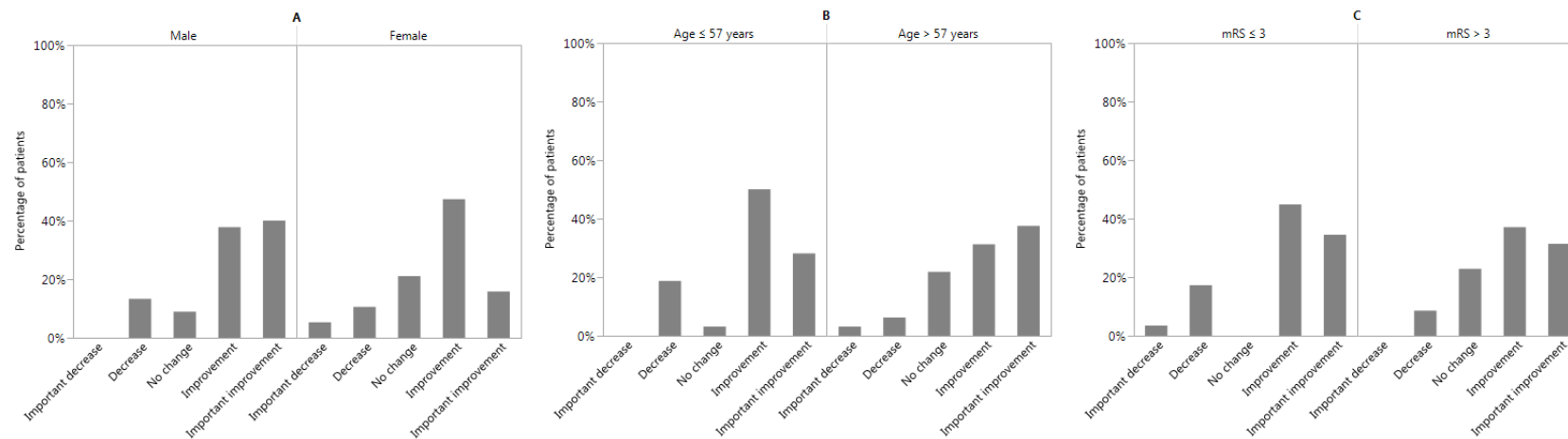


Figure 8. Percentage of participants in each t-value category between T1 and T2

Table 8. Analysis of *PM-Scale* responsiveness at global and group levels

Type of analysis	T0	T1	T2	RM ANOVA			Effect size	
	Mean (SD)	Mean (SD)	Mean (SD)	Main effect	T0 vs T1	T1 vs T2	T0 vs T1	T1 vs T2
	[CI _{95%}]	[CI _{95%}]	[CI _{95%}]	(p-value)	(p-value)	(p-value)		
Global approach (n=64)								
	41 (12) [38; 44]	45 (12) [44; 48]	53 (15) [49; 56]	<i>p</i> < .001	.010	.001	.33	.67
Group approach according to sex	<i>p</i> = .205 [†]	<i>p</i> = .205 [†]	<i>p</i> = .035 [†]					
Male (n = 45)	42 (12) [39; 46]	46 (12) [43; 50]	55 (15) [50; 59]	<i>p</i> < .001	.059	.001	.33	.75
Female (n = 19)	38 (12) [32; 44]	42 (12) [37; 48]	46 (14) [41; 54]	<i>p</i> = .002	.181	.117	.33	.25
Group approach according to patient age	<i>p</i> = .128 [†]	<i>p</i> = .016 [†]	<i>p</i> = .036 [†]					
≤ 57 years (n = 32)	43 (11) [38; 48]	49 (11) [44; 54]	58 (13) [52; 64]	<i>p</i> < .001	.024	.002	.55	.82
> 57 years (n = 32)	40 (12) [36; 44]	44 (13) [40; 47]	50 (16) [46; 55]	<i>p</i> < .001	.343	.003	.33	.46
Group approach according to patient disability	<i>p</i> < .001 [†]	<i>p</i> < .001 [†]	<i>p</i> = .048 [†]					
Minor to moderate (mRS ≤ 3) (n = 29)	51 (10) [42; 61]	59 (11) [50; 68]	62 (8) [56; 68]	<i>p</i> = .019	.012	.041	.63	.41
Severe (mRS > 3) (n = 35)	39 (11) [36; 42]	43 (11) [40; 46]	51 (16) [47; 55]	<i>p</i> < .001	.035	< .001	.26	.77

T0: at enrollment; T1: 3-months post-stroke; T2: 6-months post-stroke; SD: standard deviation; CI: confidence interval; RM ANOVA: repeated measures analysis of variance

[†] One-way ANOVA Small change  moderate change  large change 

According to disability level at enrollment. Between T0 and T1, the responsiveness of the *PM-Scale* was moderate in the “minor to moderate disability” group and it was small in the “severe disability” group (Table 8). Between T1 and T2, greater responsiveness of the *PM-Scale* was observed with the “minor to moderate disability” group exhibiting a small change and the “severe disability” exhibiting moderate change.

3.3.3. Individual evaluation

At the individual level, more than 50% of the patients exhibited improvement in *PM-Scale* measures between T0 and T1 and between T1 and T2 ($t > 0$) (Table 9). Furthermore, important improvements were observed in 19 (30%) participants ($t \geq 1.96$) between T0 and T1, and in 21 (33%) patients between T1 and T2.

Figure 7 shows the distribution of t-values in each subgroup between T0 and T1, according to patients' sex (panel A), patients' age (panel B), and patients' disability at enrollment (panel C). Overall, the evolution of patients' participation levels between T0 and T1 appears to be independent of the group. This result is consistent with the ES being nearly identical in all of the subgroups and in the entire cohort.

Figure 8 provides the percentage of patients in each t-value category for each subgroup between T1 and T2. A large proportion of the males demonstrated a “important improvement” (40%) compared to the females

(16%). Conversely, a large percentage of females were included in the “no change” category (21% vs. 9%, respectively) , while the percentage of females versus males in the “decrease” category were similar (11% vs. 13%, respectively). Figure 8 also demonstrates that a large proportion of the younger patients (e.g. ≤ 57 years) presented either “important improvement” (28%) or “improvement” (50%), while only 3% exhibited “no change” and none of the patients decreased. In the > 57 years group, “important improvement” (34%) and “improvement” (31%) were observed, while a large proportion of patients also showed “no change” (22%). The latter (22%) was a much higher percentage compared to the ≤ 57 years group (3%). For minor or moderately disabled patients at enrollment, large improvements between T1 and T2 were observed and these were classified as “important improvement” (34%) or “improvement” (45%). The percentages for the same classifications for the group of severe disabled patients were 31% and 37%, respectively. Meanwhile, in the severely disabled patient group, 23% showed “no change” between T1 and T2, while none of the patients in the “minor and moderate” group showed “no change” during the same period.

Table 9. Analysis of *PM-Scale* responsiveness at the individual level

T-value category		n	T0 Mean(SD)	T1 Mean(SD)	ES	n	T1 Mean(SD)	T2 Mean(SD)	ES
$t \geq 1.96$	Important improvement	19	35 (8)	53 (10)	2.13	21	44 (10)	62 (12)	1.8
$0 < t < 1.96$	Improvement	17	39 (13)	46 (13)	.56	26	47 (8)	53 (9)	.78
$t = 0$	No change	5	32 (14)	32 (14)	—	8	33 (12)	33 (12)	—
$-1.96 < t < 0$	Decrease	19	47 (9)	41 (9)	.67	8	55 (19)	49 (21)	.32
$t < -1.96$	Important decrease	4	55 (11)	39 (12)	1.45	1	—	—	—

T0: at enrollment; T1: 3-months post-stroke; T2: 6-months post-stroke; SD: standard deviation; ES: effective size

Small change  moderate change  large change 

3.4. Discussion

This study examined the responsiveness of the *PM-Scale* to changes in participation in stroke patients in Africa. Patients were followed over six months without any specific intervention targeting their participation. Participation was evaluated at global, group, and individual levels. The results obtained show that the *PM-Scale* is sensitive to change and can detect minor and relevant changes in patients over time.

When a global approach was used to analyze the *PM-Scale* data (Table 8), 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, the global approach has the potential to mask important information since data are pooled and distinctions are not made between groups and individuals. For this reason, we also performed group-based and individual-based analyses which revealed further details of the present data.

Between T1 and T2, ES was greater in the male subgroup (.75) than in the female subgroup (.25). Further analyses suggested that the ages and severity of disability for these males did not significantly differ from those of the females. In Nigeria, Vincent-Onabajo and colleagues (Vincent-Onabajo, Hamzat, et al. 2014) also found that participation levels differed between

males and females, although not significantly. The males had slightly higher median scores with the London Handicap Scale between 1 and 9 months of follow-up (Vincent-Onabajo, Hamzat, et al. 2014). 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 social isolation as a widow (Boden-Albala et al. 2005). 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 (Vincent-Onabajo, Owolabi, et al. 2014). It has also been hypothesized that pre-existing restrictions may impact post-stroke outcomes (Kalichman et al. 2007). 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, men 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 compared with women. Conversely, women are more stimulated to participate in household, trade, and care for children. All this suggests that in African communities, improvement of female stroke

patients' participation could require not only an upstream action whereby healthy women are given opportunities to be more engaged in community, social, and civic life activities, but also could require a particular attention to the improvement of ability in activities related to household, trade, and care for children.

Age is one of the critical risk factors of stroke. In general, older patients present more severe post-stroke neurological and behavioral deficits than younger patients (Benjamin et al. 2017). However, Desrosiers and associates have suggested that reduced participation after stroke may partly be attributed to normal aging and not entirely to the stroke itself (Desrosiers et al. 2005). They observed that in healthy community-dwelling people aged 55 years and older, social participation significantly decreased with advancing age (Desrosiers et al. 2004). In the present study, younger subjects consistently showed greater improvement in their participation levels with the *PM-Scale* than older subjects. Moreover, younger participants demonstrated large ES values between T1 and T2, while the ES was small in the older patients over the 6-month study period. As observed in our study and several previous studies, stroke occurs earlier in African communities compared to occidental communities (Ezejimofor et al. 2016; Kossi et al. 2016; Kossi, Nindorera, et al. 2017a; Vincent-Onabajo, Hamzat, et al. 2014). Therefore, cost-effective and suitable programs for younger

individuals could considerably boost participation after stroke in community-dwelling patients in Africa.

In this study, all the groups exhibited improved participation over time. However, consistent with the individual approach used in previous studies (Batcho et al. 2011; Batcho et al. 2014; Vandervelde et al. 2009), 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 their 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 (Kossi, Nindorera, et al. 2017a). Evaluations of individual-reported participation levels also provided the opportunity to add classification categories such as “importantly improved” and “importantly decreased” to “improved”, “no change (stable)”, and “decreased”. As shown in Table 9, our data clearly indicate that the *PM-Scale* measured different magnitudes of participation change in the examined stroke patients.

Instruments that are responsive to patients with severe or mild disabilities are required for clinical follow-up. Indeed, due to a ceiling effect, many scales are useless in clinical trials that enroll patients with intermediate

disease conditions. In the present study, good sensitivity to changes in participation were 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.

3.5. Conclusions

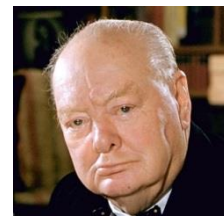
Tracking changes in participation in patients with chronic diseases is an important consideration in rehabilitation care. In the present study, different statistical indices and methodological approaches were combined to investigate the responsiveness of the *PM-Scale*, a simple patient-reported questionnaire measuring participation. The *PM-Scale* showed good responsiveness and can be used to track changes that occur in people with stroke in Africa. In addition, the *PM-Scale* can be used to evaluate the effects of clinical interventions on participation and to guide various stages of health service provision, including assessment, goal setting, and program planning, for individuals and groups in Africa.

Chapter IV

Factors associated with participation during the first 6 months after stroke in Benin.

« Le succès n'est pas final, l'échec n'est pas fatal: c'est le courage de continuer qui compte ».

Winston Churchill



Factors associated with participation during the first 6 months after stroke in Benin.⁵

4.1. Abstract

Objective: To investigate the relationships between impairments, activity, and participation over the first six months after stroke.

Design: A six-month observational study with three evaluation time points (1 month, 3 months, and 6 months). Correlations were investigated between variables at each evaluation time and multivariable linear regressions were performed.

Setting: Rehabilitation centers.

Participants: Stroke patients (N = 64); mean age $\pm$ standard deviation = 56.9 $\pm$ 12.6 years; 70% male.

Intervention: Not applicable.

Main outcome measures: Participants were evaluated using the *PM-Scale*, the *ACTIVILIM-Stroke*, the *Stroke Impairment Assessment Set* (SIAS), the *6-Minute Walk Test* (6-MWT), and the *modified Rankin Scale* (mRS).

⁵ Article in preparation

Results: The ACTIVLIM-Stroke measure was the best predictive variable of the subject's participation level at each evaluation time point. At 1 month, the aphasia was the second factor associated with participation. At 3 months, the second best explanatory variables was the 6-MWT. At 6 months, in addition to the ACTIVLIM-Stroke, the SIAS and the mRS were associated with the participation measures.

Conclusions: The ability to carry out activity of daily living, as measured by the ACTIVLIM-Stroke measures seems to be the main factors explaining participation during the first 6 months in community-dwelling stroke survivors in Benin. In this context, rehabilitation programs should be more oriented to functional tasks in order to improve the patients' autonomy and participation.

Keywords: Stroke ■ Relationships ■ Impairment ■ Activity ■ Participation

4.2. Introduction

Stroke is a principal cause of long-term disability and the third most common cause of death (Bonita 1992; Luo et al. 2017). The impact of stroke on an individual's functioning may be evaluated using the conceptual framework of International Classification of Functioning, disability and Health (ICF), taking into account body functions and structures, activities, and participation (WHO 2001). In rehabilitation, the assessment and understanding of participation and its major determinants is essential not only to understanding the broad health-related impacts of chronic illness or conditions, but to evaluate the effectiveness of rehabilitation interventions. Much of rehabilitation practice is based on the presumption that rehabilitation interventions acting at the levels of disease, body structures, and impairments, and/or a person's function should be reflected in changes in that person's participation (Desrosiers et al. 2002). The ICF framework, also suggests that participation is influenced by the personal characteristics of an individual as well as the environmental context that represents a person's social and physical circumstances. In the African context, almost all stroke patients return to their community and live at home, after hospital discharge (Olaleye et al. 2014; Kaseke et al. 2017). Taking these aspects into consideration, interventions during stroke rehabilitation should seek to promote good reintegration and participation in community as early as possible.

Recovery after stroke is recognized as a complex process and the time since onset influences this recovery (Jorgensen et al. 1995b, 1995a; Dawson et al. 2007; Kossi et al. 2016). During the first six months, stroke survivors generally have to cope with various challenges of physical, functional, and social levels resulting in increased activity limitations and participation restrictions (Kossi et al. 2016; Meyer et al. 2016; Sommerfeld et al. 2004). Several instruments have been designed to evaluate body functions and structures (Zigmond et al. 1983; Liu et al. 2002) and activities (Mahoney et al. 1965; Batcho et al. 2012; Kervio et al. 2003). Recently, a new tool has been developed for the measurement of participation after stroke in the African context (Kossi, Nindorera, et al. 2017b). This offers clinicians and researchers in Africa an interesting opportunity to evaluate adequately the participation in stroke survivors.

According to the ICF, changes in one dimension (body functions and structures, activity, participation, or contextual factors) have the potential to influence and modify one or more dimensions, but not always in a predictable manner. Several studies have investigated the relationships between impairments and activities in stroke patients, (Levine et al. 2014; Mullick et al. 2015; Patterson et al. 2016; Batcho et al. 2013). So far, little is known about the relationships between these dimensions and participation in stroke survivors, particularly in the African context. Therefore the present

study aimed to investigate relationships between impairments, activity limitations and participation during the first 6 months after stroke in the Republic of Benin.

4.3. Methods

4.3.1 Ethical considerations and inclusion criteria

This 6-month observational cohort study was approved by the Ethic Committee of the Université catholique de Louvain (Belgium) and local ethics committees in Benin (Africa). Participants were recruited from patients' registers of three rehabilitation centers in Benin. Subjects were eligible for inclusion if they met the following criteria: *i)* unilateral hemiplegia/paresis subsequent to a stroke experienced within 30 days, *ii)* absence of major cognitive impairments that could prevent the patient from responding in a face-to-face interview (Community Screening Instrument for Dementia (Prince et al. 2011) score ≥ 7), *iii)* at least 18 years of age, and *iv)* living in a community (at home). Selected patients signed a consent form and both baseline and follow-up assessments were conducted between November 2015 and April 2016.

4.3.2. Procedure and conceptual framework

During the follow-up process, each patient was evaluated at three time-points: at 1 month post-stroke (T0), 3-months post-stroke (T1), and 6-months post-stroke (T2). The ICF model was used as a conceptual

framework to assess the functioning of the stroke patients. The patient's participation, as well as other ICF dimensions were assessed at each of the 3 aforementioned phases.

4.3.2.1. Assessment of body functions

Various aspects of stroke impairments were measured by the Stroke Impairment Assessment Set (SIAS) including spasticity, language function (aphasia), motor function of the upper and lower limbs, etc. All the 22 SIAS items are rated from 0 (severely impaired) to 3 (normal), except the motor function of the upper and lower limbs items that were rated from 0 (severely impaired) to 5 (normal). SIAS total scores range from 0 (severely impaired) to 76 (normal) corresponding to the summation of the individual item scores.(Chino et al. 1995) Depression was measured by the Hospital Anxiety and Depression Scale (HADS) (Zigmond et al. 1983). The HADS is a self-assessment scale developed to detect states of depression and anxiety. In this study, only the depressive subscale was used to verify the severity of mood disorders. A higher HADS score represents a more depressive status; scores over 11 usually indicate a mood disorder.

4.3.2.2. Activity assessment

Activity limitations were measured with the 20-item ACTIVILIM-Stroke scale (Batcho et al. 2012) that measures the "overall independence in activities of daily living (ADLs)" in adults with stroke. This instrument was validated

previously by a Rasch analysis in a sample of stroke patients from Benin and Belgium and was found to possess good psychometric qualities (validity, unidimensionality, reliability, linearity, and invariance). Walking ability, which belongs to activities was measured with the 6-MWT (Kosak et al. 2005). Scores on the 6-MWT were transformed in a walking velocity index (meter/min). Walking ability has been considered fundamental for ADLs and social participation, (Chiou et al. 1985) reflecting an individual's health and functional states (Abellan van Kan et al. 2009). The overall level of disability was ranked by the modified Rankin Scale, which is an ordinal clinician-rated scale that categorizes severity of disability on 7 levels, from 0 ("no symptoms at all") to 6 ("dead").

4.3.2.3. Participation assessment

Participation was evaluated by the Participation Measurement Scale (*PM-Scale*) (Kossi, Nindorera, et al. 2017a) which consists of 22 items referring to daily situations encountered by stroke patients in Africa. The *PM-Scale* was administered in face-to-face interviews to our sample. Participants were asked to provide their perceived participation on a 3-level scale: not at all (score = 0), weakly (score = 1); strongly (score = 2). The *PM-Scale* and its applications and advantages have been described in detail elsewhere (Kossi, Nindorera, et al. 2017a; Kossi and Thonnard 2017b). In short, the *PM-Scale* is an ICF-based and Rasch-built measure allowing converting

ordinal raw scores into interval-level measures (in logit and in centiles), on a unidimensional scale. In this study we used the centiles metric transformation of the *PM-Scale* raw scores because this is more common and might be easier to be understood by clinicians and researchers who are not familiar with the Rasch model. Higher scores indicate higher participation level.

4.3.3. Sample and statistical analyses

Sixty-fours eligible patients agreed to participate and were enrolled in the study, 45 males and 19 females with a mean age $\pm$ SD of 56.84 ± 12.6 years. Time since stroke $\pm$ SD was 24.25 ± 6.1 days. Thirty patients presented left paretic side while 34 had the right side affected.

Descriptive statistics were used to determine the extent of the stroke patients' body functions, activity, and participation. Normality of the data was checked with the Shapiro-Wilk test, while the Levene test was used to investigate the homogeneity of variances. Patients' scores were statistically compared at consecutive assessment time points by using repeated measure analysis of variance (RM-ANOVA) with an honest significant difference (HSD) Tukey post-hoc automatic correction for multiple comparisons. The strengths of the linear associations between the participation measures and the body functions and activity were determined using Spearman or Pearson correlations coefficients according to the type

of variable. All the variables that were significantly (conservative level of significance of 0.2) related to subjects' participation were included in a multiple forward stepwise linear regression to build the best predictive equation of participation. The adjusted coefficient of determination, which considers the number of selected variables, was used to avoid overestimating the true predictive variance of the regression equation. Interactions between variables were also checked and included in the equation if statistically significant.

Statistical analyses were performed using the R software.

4.4. Results

Table 10 displays the sample's characteristics and body functions, activity, and participation at 1, 3, and 6 months. Significant changes were observed over time in impairments except in spasticity and in aphasia where changes were not significant. Walking velocity (as measured by the 6-MWT) and activity limitations (as measured by the ACTIVLIM-Stroke) significantly increased over the 6 months. The overall level of disability measured by the MRS significantly decreased over time indicating an improvement of the subjects' status. The participation level measured by the *PM-Scale* showed a significant increase over the follow-up time.

Table 11 gives the correlations between the ICF impairments, activity limitations and participation restrictions over time, while. Sex was

associated with participation but not significantly, with men participating slightly more than women. The paresis side were not significantly correlated with the participation level. Age was significantly correlated with participation at 3 months and 6 months, but not at 1 month. Younger subjects participated significantly more than older subjects. Nevertheless, both age and the paresis side were not included in the final model of prediction of participation (Figure 9 and Figure 10).

All the impairments were significantly associated with participation over the 6 months. The more subjects were impaired, the less they participate. However, only the aphasia was included in the final model of prediction of participation at 1 month, and the SIAS score at 6 months.

The activities limitations, the walking velocity and the overall disability (MRS score) were also significantly associated with the participation over time. The activity limitations were the best predictor of participation over time. The walking velocity was the second best predictor at 3 month and the overall disability was the second best predictor at 6 mois.

Table 10: Clinical characteristics of the sample

		T0	T1	T2	RM-ANOVA	Correlation coefficients			
		Median [P25; P75]	Median [P25; P75]	Median [P25; P75]	(p-value)	(R; p-value)			
					Main Effect	T0vsT1	T1vsT2	T0vsT1	T1vsT2
Body functions	Upper Extremity #	4 [1; 6]	5 [3; 7]	6 [4; 8]	< .001	< .001	< .001	.88; < .001	.94; < .001
	Lower Extremity #	7[5; 10]	10 [8; 12]	12 [10; 14]	< .001	< .001	< .001	.83; < .001	.91; < .001
	Spasticity #	2 [1; 3]	2 [2; 3]	3 [2; 3]	< .001	.484 ^{NS}	.406 ^{NS}	.70; < .001	.86; < .001
	Aphasia #	2 [1; 3]	2 [2; 3]	3 [2; 3]	< .001	.381 ^{NS}	.457 ^{NS}	.89; < .001	.84; < .001
	SIAS #	29 [23; 36]	34 [30; 40]	40 [36; 43]	< .001	< .001	< .001	.85; < .001	.91; < .001
	Depression #	13 [8; 13]	9[6; 11]	7 [5; 9]	< .001	.015	.001	.50; < .001	.75; < .001
Activities	Walking velocity (m/min), mean±SD †	18±27	30±33	44±39	< .001	< .001	< .001	.84; < .001	.91; < .001
	Activlim-stroke (%), mean±SD †	39±17	48±15	55±16	< .001	< .001	< .001	.81; < .001	.89; < .001
	MRS #	4 [3; 4]	3[2; 4]	2 [1; 3]	< .001	< .001	< .001	.78; < .001	.81; < .001
Participation	PM-Scale, mean±SD (%) †	41±12	45±12	53±15	< .001	.010	< .001	.55; < .001	.77; < .001

P25 : Percentile: 25; P75 : Percentile 75; T0 : enrollment; T1 : 3 months; T2 : 6 months; R : correlation coefficient; m/min : meter/minute

Ordinal variable, R is Spearman correlation coefficient; † Continuous variable, R is Pearson correlation coefficient

NS = Nonsignificant

Table 11: Correlations between participation, sociodemographic factors, body function and activity.

Socio-demographic and clinical data		PM-Scale (T0) (%)		PM-Scale (T1) (%)		PM-Scale (T2) (%)	
		R	p-value	R	p-value	R	p-value
Body functions	Sex (femal/male) #	-.13	.30 ^{NS}	-.07	.60 ^{NS}	-.21	.09 ^{NS}
	Age (years) †	-.14	.26 ^{NS}	-.29	.02	-.26	.03
	Paresis side #	.12	.36 ^{NS}	-.03	.83 ^{NS}	.07	.57 ^{NS}
	Upper Extremity #	.30	.02	.63	< .001	.68	< .001
	Lower Extremity #	.45	.001	.61	< .001	.73	< .001
	Spasticity #	.25	.04	.34	.006	.32	.008
	Aphasia #	.42	.001	.31	.01	.43	< .001
	SIAS #	.46	< .001	.64	< .001	.78	< .001
	Depression #	-.36	.004	-.61	< .001	-.60	< .001
Activity	Walk velocity (m/min) †	.56	< .001	.69	< .001	.71	< .001
	Activlim-stroke (%) †	.63	< .001	.79	< .001	.82	< .001
	MRS #	-.58	< .001	-.73	< .001	-.82	< .001

T0 : enrollment; T1 : 3 months; T2 : 6 months; R : correlation coefficient; m/min : meter/minute

Ordinal variable; R is Spearman correlation coefficient

† Continuous variable; R is Pearson correlation coefficient

NS = Nonsignificant

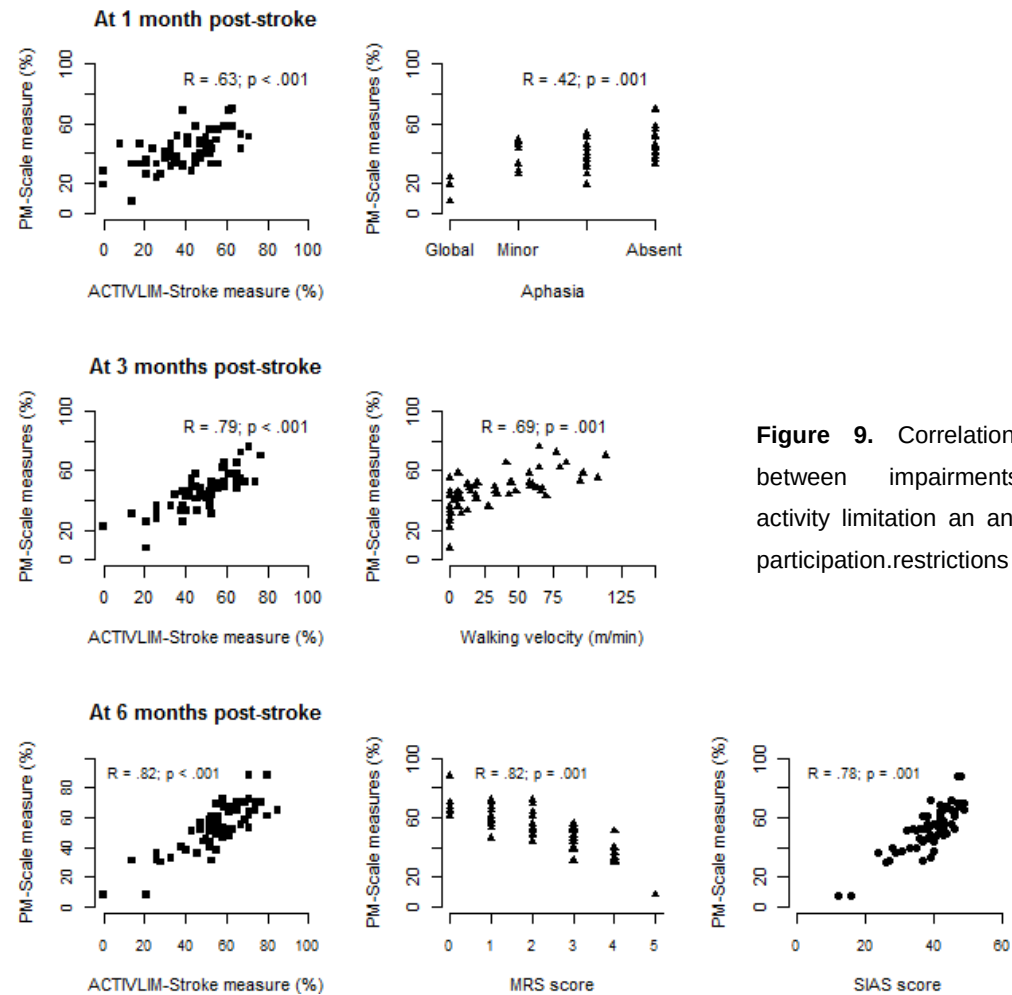


Figure 9. Correlations between impairments, activity limitation and participation restrictions

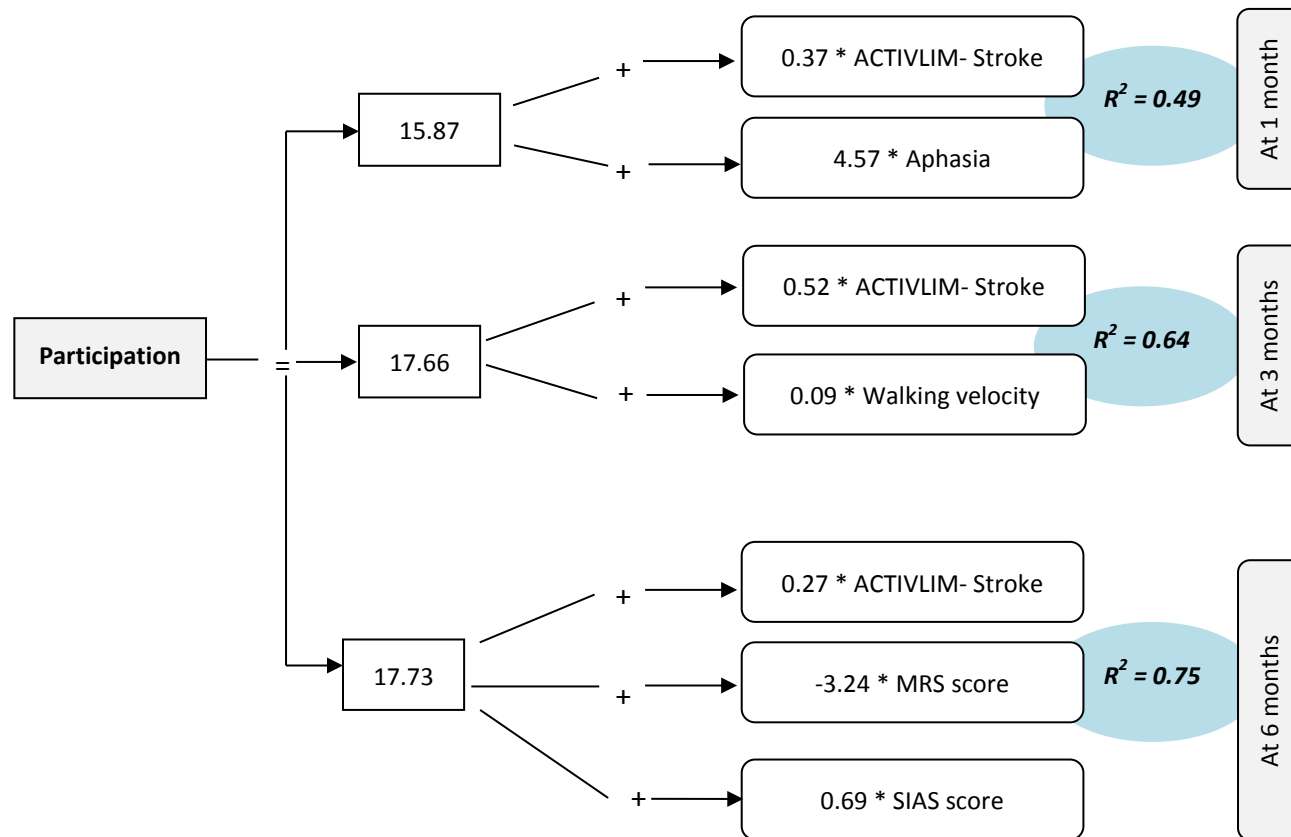


Figure 10. Final model of participation during the first 6 months after stroke

4.5. Discussion

This study aimed to examine the relationships between participation and the other dimensions of ICF in a sample of 64 patients from Republic of Benin during the first 6 months after stroke. Three evaluations have been conducted: at 1 month (T0), at 3 months (T1), and at 6 months (T2). Results showed that activity limitations, as measured by the ACTIVLIM-Stroke was associated with participation during the first 6 months. At 1 month, the activity limitations and the aphasia were the best predictors of participation. At 3 month the best predictors were the activity limitations and the walking ability as measured by the 6-MWT. At 6 months the activity limitations, the overall disability as measured by the MRS and the SIAS score were the best predictors.

At 1 month, the median score of the sample on SIAS was 29 over 76. Most subjects were “critically” ill as often during the first weeks post-stroke. The mean ACTIVLIM-Stroke and *PM-Scale* measures were both low ($39\pm17\%$ and $41\pm17\%$ respectively). The multivariate linear regression model showed that the ability of patients to carry out ADLs, as measured by the ACTIVLIM-Stroke scale and the aphasia were important factors explaining subjects’ participation. This may be a usefull information since little is known about the process by which participation evolves soon after hospital discharge, specially in the African context. However, short-term improvement in patients’ functioning is critical because this is the period

when patients remain in contact with the health care system and can still benefit from regular rehabilitation program to promote recovery over the long term. Results of this study showed that in order to promote early participation it would be important to emphasize the functional autonomy and to recovery language for better communication between patients and others. Indeed, communication belongs to the 9 domains of participation and its deficit would affect social interactions between the patient and its entourage and could therefore hinder subject's participation (Viscogliosi et al. 2011).

The mean participation level in our sample increased from 41 ± 12 at 1 month to 45 ± 12 at 3 months ($p < .001$). Furthermore, the activity limitations and the walking ability were likely to determine the participation level at 3 months. Indeed, outcomes at 3 months are very critical in stroke rehabilitation because it means the end of the short-term and gives opportunity to resume the abilities of the patients in usual ADLs. Previous studies indicated that the ability to walk after stroke is associated with the ability to carry out ADLs, social participation, and quality of life 3 to 6 months after the stroke (Benito Garcia et al. 2015; Langhammer et al. 2008; Aziz et al. 2008). Moreover, in 2 previous studies, Desrosiers and colleagues also found that physical abilities, (eg, balance, lower extremity motor coordination, walking endurance, and upper extremity function) were

among the best predictors of participation of people who had a stroke (Desrosiers et al. 2002; Desrosiers et al. 2006). Indeed, hemiparesis is one of the most common impairments after stroke and contributes to activity limitations such as reduced gait performance, (Richards et al. 1999; Flansbjer et al. 2006) which in turn can lead to restrictions in perceived participation (Danielsson et al. 2011). Even if a majority of stroke survivors are able to walk independently 6 months after stroke, (Veerbeek et al. 2011; Kollen et al. 2006) many cannot walk with sufficient speed, have to use walking aids, and are restricted in their indoor and outdoor mobility at 3 months (Lord et al. 2006; Carvalho et al. 2010). The results of our study also confirm that it would be interesting to promote community-based brisk walking in stroke survivors from 3 months after stroke (Batcho et al. 2013).

At 6 months, important predictive factors of participation were the activity limitations, the overall level of impairment as measured by the SIAS and the overall level of disability as measured by the MRS. This findings reinforce the fact that participation is a holistic concept reflecting the combined effect of the different levels of individual functioning as described in the ICF framework. Indeed, participation after stroke is a promising concept for research in rehabilitation sciences since it considers not only daily activities that are essential for survival (e.g., feeding, personal care, mobility, communication) but also social roles that are mainly required for

well-being (e.g., interpersonal relationships, leisure) (Desrosiers et al. 2004; Desrosiers et al. 2005). A study carried out with 189 adults over 65 years of age who were no longer physically independent, showed that the disability domains evaluated in Functional Independence Measures are all included in the concept of participation, but that the reverse is not true since the latter encompasses significant additional components (Desrosiers et al. 2004). These data support the idea that it is important to go beyond disability measures to correctly evaluate overall functioning of people who have a stroke.

Study limitations

The present study was limited by the fact that causality could not be determined using correlation coefficients and multiple linear regression analysis. As a result, we cannot state that 75% of the variance observed in participation measures at 6 months results directly from activity limitations, impairments, and disability. The size of the sample involved in this study precludes a structural equation modeling. Another limitation of the present study lies in the fact that it cannot be generalized to patients with major cognitive impairments because such patients were excluded from the study cohort.

4.6. Conclusion

Measuring the level of participation after stroke goes beyond the idea of functional independence because participation is dependent on both impairments, activity limitations, and contextual factors. By identifying factors that are related to participation in an African country, the current study suggests that rehabilitation clinicians in this area as elsewhere should concentrate on abilities that are modifiable by interventions, such as walking ability and autonomy in ADLs, and be aware of others that they have no control over, such as age and initial neurological severity of the stroke.

Chapter V

General Discussion

« L'avenir d'un enfant est l'oeuvre de sa mère ».

Napoléon Bonaparte



Stroke is a major cause of long-term disability throughout the world. It affects everyday life for both the stroke victims and their families. In an epidemiological point of view, recent estimates report about 25.7 million stroke survivors, 6.5 million deaths from stroke every year, 113 million disability adjusted life years (DALYs) due to stroke, and 10.3 million new strokes per year (Feigin et al. 2017). Despite the development of continuous efforts to improve systems to recognize stroke symptoms and deliver care promptly, only a minority of patients with stroke in developing countries can receive appropriate treatment, and many of them remain with moderate to important residual functional deficits (Winstein et al. 2016; Kossi et al. 2016). Thus, the need for effective stroke rehabilitation is likely to remain an essential part of the continuum of stroke care mainly in low-income countries. Because stroke is fundamentally a chronic condition, the end of formal rehabilitation (commonly by 3–4 months after stroke) should not mean the end of the restorative process. In many respects, stroke has been managed medically as a temporary or transient condition instead of a chronic condition that warrants monitoring after the acute event (Sakakibara et al. 2017). Currently, unmet needs persist in many domains, including social reintegration and participation, health-related quality of life, maintenance of activity, and self-efficacy (i.e., belief in one's capability to carry out a behavior) (Kamalakannan et al. 2016; Shannon et al. 2016). A Guideline for adult stroke rehabilitation and

recovery (Winstein et al. 2016) endorsed by the American Academy of Physical Medicine and Rehabilitation and the American Society of Neurorehabilitation, emphasizes some major points to be addressed, such as the rehabilitation program, including system-level sections (e.g., organization, levels of care); the prevention and medical management of comorbidities, the assessment of impairments and activities (treatment/interventions); and the transitions in care and community rehabilitation, focused primarily on the participation level of the ICF. The overall aim of this thesis lies in the context of this guideline and aims to contribute to the strengthening of the management and the comprehensive rehabilitation care for the post-stroke patient in Africa. Indeed, by providing a sociocultural-tailored tool for the measurement of participation in Africa, this thesis will contribute in the monitoring of the effects of interventions on the patients' participation in the society. Hereafter, we will discuss the strengths and weaknesses of the three studies we have carried out to achieve our overall objective.

In the first and the second studies of this thesis we developed and investigated the initial psychometric properties of the Participation Measurement Scale (*PM-Scale*) (Kossi and Thonnard 2017a; Kossi, Nindorera, et al. 2017b). Indeed, there is a dearth of stroke-specific tools with solid psychometric properties suitable to the African context. Yet health

care professionals are aware that the use of well-adapted tools is a very important criterion in the context of a therapeutic decision and in the patients' monitoring in rehabilitation as in other domains. In Chapter II of this thesis we described the use of the Rasch model to develop and validate a new scale for the measurement of participation in adults with stroke in Africa. A preliminary list of 100 items of the Participation Measurement Scale was developed and submitted to participants in French. After successive Rasch analyses, 22 items were retained for the final *PM-Scale*. The final scale exhibited good psychometric properties including range of measurement in our sample, reliability, unidimensionality, and invariance in our sample. The Rasch model was chosen as the measurement framework because it is based on the principle of fundamental measurement, the type of measurement taken for granted in the physical sciences (Andrich 2004). The possibility of transformation of *PM-Scale* raw scores into interval-level measures in logit or in centiles allows quantitative parametric statistics and arithmetic comparisons between and within individuals. These operations are strongly preferred in research setting for better interpretation of results and measurement of change. Moreover, implications of these operations go beyond mathematical and statistical aspects. Particularly, the interval-level properties of participation measures have relevance in clinical practice. They imply that a difference of one unit of measurement between two measures represents

the same amount of participation throughout the scale, allowing meaningful quantitative comparisons between and within subjects. Furthermore, the relatively high size of the sample (276 subjects) involved in the validation study of the *PM-Scale* and the cross-country aspect of the study (Benin, West Africa and Burundi, East Africa) strengthens our conclusions on the psychometric qualities of the *PM-Scale*. Finally, to enable a wide use of the scale and for publication reasons, an English translation of the questionnaire has been made. The content of the hierarchical scale was consistent with previous scales in other sociocultural contexts (Bouffoulx et al. 2008; Heinemann et al. 2011) and indicated that more difficult situations were related to community, social and civic life (e.g, “occupy a position of responsibility in my religion organization”; “engage myself in a neighbourhood association”). This finding suggests that overall the domains of participation are common, regardless of the culture or continent; but only the content of domains (items) change. Accordingly, improvement of participation after stroke in Africa, may demand particular intervention on religious and associations aspects of life (Kossi, Nindorera, et al. 2017b).

Africa is so full of culture, with it not only changing from one country to another, but within a single country, many cultures can be discovered. Even though African cultures are widely diverse, it is also, when closely studied, seen to have many similarities. For example, the morals they uphold, their

love and respect for their culture as well as the strong respect they hold for the aged and disabled people are very similar. So, ethnic diversity in Africa would not be a limit for the applicability of the PM-Scale everywhere in the continent, because whatever the ethnic group and the religion, the same values are generally shared.

Whatever the cultural context, measurement of participation is important in physical therapy and rehabilitation because participation is among the endpoints of all intervention. Several studies suggest that participation is likely to be more important for all disabled subject than impairment itself (Rivers et al. 2017; Vega-Ramirez et al. 2017). Currently, the nature and organization of rehabilitation cares in the most African countries are very limited to the impairment aspects of treatment. Several regions in Africa lack of rehabilitation professionals like physical and rehabilitation doctors, physical, speech and occupational therapists who are particularly important for social and professional reintegration after a long-term or a chronic disease as stroke (Adoukonou et al. 2010; SASW 2000). Fortunately, in the most African communities the social support is valuable. The cultures encourage extended family networks and kinships, so isolation of people with disabilities like stroke is not common. People encourage their relatives with disabilities to live with them in their homes or make provision for other members of the family to live with them (Obembe et al. 2010; Walsh et al. 2015; Akosile et al. 2016). Indeed, a recent study investigating the factors

associated with community reintegration among stroke survivors in Nigeria found that social support was highly involved in the participation of individuals in the community (Akosile et al. 2016).

The *PM-Scale* is designed to be administered by face-to-face interview. However, results from a recent study showed that in many African countries, more notably in Western and Central Africa, a relatively small percentage of adults can read (Smith-Greenaway 2015). Interviewer-administered questionnaires may therefore be problematic to apply in some areas, mainly in rural regions. In addition, some stroke patients will be unable to respond to an interview setting due to important cognitive impairments. Consequently, the possibility of using proxies (relative or close friend) seems to be relevant when interviews and self-reports are not possible (Dorman et al. 1997; Segal et al. 1994; Wild D 1997). So, we suggest that further studies investigate the possibility and the reliability of self-report and proxy-respondent procedures with the *PM-Scale*.

In the third study of this work we analyzed the relationships between impairments, activities and participation, and proposed an equation of prediction of participation from the former variables. This study shown that activity limitations are the main predictive variable of the participation during the first 6 months following a stroke explaining 40% the variance of participation in a sample of Beninese subjects. This would be a promising

information for physical therapists since they may be aware that even if they cannot directly rehabilitate subjects' participation in the community, they can improve their participation by working on the recovery of functional activities. In return, by improving the subjects autonomy in activities, they could improve their participation in community. The main perspective after this work would be to test how well a program of intensive rehabilitation could improve subjects' participation versus a traditional program of rehabilitation in stroke survivors in Africa. In fact, several studies have shown that exercise confers health benefits even years after stroke so that physical activity should be encouraged regardless of how much time has elapsed since stroke onset (Globas et al. 2012; Gjellesvik et al. 2012). Thus, it should be interesting to initiate physical activity programs to promote cardiovascular fitness after stroke in some African countries and evaluate their effect on the participation level. These programs should be cost-effective, because as a chronic disease, stroke rehabilitation is a very heavy burden for patients, their family, and the society. Because almost 100% of stroke survivors in Africa live in the community, and most of them at home, (Aziz et al. 2008) home and community-based programs seem to be more appropriate for chronic stroke management in Africa. Successful intervention in the community will require careful assessment of the match between patient needs and the availability of formal and informal resources. Referral to appropriate local community resources can help to

support the needs and priorities of the patient and the family or caregiver (Barker et al. 2010). Myths and barriers about exercise (exercise is unsafe, causes second stroke, increases fatigability) (Morris et al. 2012; Rimmer et al. 2008; Nicholson et al. 2013) need to be dispelled in the process of rehabilitation. There is substantial evidence that rehabilitation services, particularly exercise-based programs, provided in the community after discharge from acute or institutional care can improve cardiovascular health and decrease the risk of cardiovascular events, leading to increased functional autonomy (Batcho et al. 2013) and short-term survival rates for individuals who have experienced a stroke. Yet, its impact on participation and quality of life in the African context remains to be proved. Finally, stroke survivors who are unable to exercise will need alternative solutions to maintain an active and engaged lifestyle.

Benefits associated with community and home-based rehabilitation programs have been reported for a variety of outcomes, including reduced costs, decreased length of stay in hospitals or institutional settings, more opportunity for patient and family involvement in the treatment process, and less stress on caregivers and family members (Marsden et al. 2016; Ytterberg et al. 2010). It has also been consistently reported that individuals recovering from a stroke and their family members or caregivers prefer home or community-based rehabilitation programs over

center or institutionally located rehabilitation services for a variety of practical and personal reasons (Hillier et al. 2010).

Regardless the rehabilitation actions, upstream strategies to instill long-term commitment to a physically active lifestyle should be initiated not only in the healthy population but also in stroke population, particularly during formal stroke rehabilitation. Early participation in physical activity programs and education on lifestyle choices, risk factor reduction (alcohol consumption), and secondary prevention may facilitate uptake of healthy behaviors.

In United States, the percentage of individuals who were working before their stroke who return to work after stroke varies widely across studies, from 20% (Hofgren et al. 2007) to 66% (Hommel et al. 2009). It should also be interesting to evaluate return to work after stroke in African communities. This is particularly important because there are substantial prove of early occurrence of stroke in African communities (55 – 60 years of age) compare with occidental communities (70 years of age). Early occurrence of stroke in Africa means more probability of occurrence in an active population. As a consequence, actions to promote return to work after stroke should be investigated.

Appendices

Participation Measurement Scale (PM-Scale) *(in English)*

Identification: **Date** |__|__||__|__| 201__

Could you please indicate the level of your involvement in each of the following situations?

Tick “?” for unfamiliar situations you cannot estimate your involvement (because you never meet them, not because you have not capability to involve yourself).

Items	Not at all	Weakly	Strongly	?
1. understand a gesture of goodbye				
2. clearly understand ideas of others				
3. express my gratitude to someone				
4. make a simple mental arithmetic (e.g. 10 + 10)				
5. choose clothing appropriate to the climate				
6. know how to express my disagreement in a proper way				
7. go to the hospital for care				
8. choose my occupations based on priorities				
9. choose my job based on my physical abilities				
10. have hope in my future				
11. have confidence in myself				
12. have a clean physical appearance				

13. keep my accounts				
14. clearly understand the content of a letter				
15. have a balanced and varied diet				
16. involve myself in the decisions making of my entourage				
17. help people to find a solution to a crisis				
18. participate in caring for my children or grandchildren				
19. speak to an audience				
20. participate in religious feasts				
21. engage myself in a neighbourhood association				
22. occupy a position of responsibility in my religion organization				

Participation Measurement Scale (PM-Scale) (en Français)

Identification : Date |_|_|||_|_|| 201_

Pourriez-vous, s'il vous plaît, indiquer le niveau de votre implication à chacune des situations suivantes?

Cochez “?” pour les situations qui ne vous sont pas familières et dont vous ne pouvez pas estimer votre implication.

Items	Pas du tout	Fablement	Fortement	?
1. comprendre un geste d'au revoir				
2. comprendre clairement les idées des autres				
3. exprimer ma gratitude à quelqu'un				
4. faire un calcul mental simple (e.g. 10 + 10)				
5. choisir l'habillement approprié au climat				
6. savoir exprimer mon désaccord d'une manière appropriée				
7. me rendre à l'hôpital pour des soins				
8. choisir mes occupations en fonction des priorités				
9. choisir mon travail en fonction de ma capacité physique				
10. avoir bon espoir en mon avenir				
11. avoir confiance en moi-même				
12. soigner mon apparence physique				
13. gérer mon argent				
14. comprendre clairement le contenu d'une lettre				

15. avoir une alimentation équilibrée et variée				
16. m'impliquer dans les prises de décision de mon entourage				
17. aider des personnes à trouver une solution à une crise				
18. participer aux soins apportés à mes enfants et petits enfants				
19. prendre la parole devant un public				
20. participer à des fêtes religieuses				
21. m'engager dans une association de quartier				
22. occuper un poste de responsabilité dans ma religion				

Table 12: Conversion of raw scores into interval measures in logit and in centiles

Raw scores	Interval measures	
	logit	Centile (%)
0	-6.56	0
1	-5.66	8
2	-5.01	13
3	-4.54	16
4	-4.16	19
5	-3.83	22
6	-3.54	24
7	-3.27	26
8	-3.01	28
9	-2.77	30
10	-2.53	31
11	-2.30	33
12	-2.28	33
13	-1.85	36
14	-1.63	38
15	-1.41	40
16	-1.19	41
17	-0.98	43
18	-0.77	44
19	-0.57	46
20	-0.36	48
21	-0.16	49
22	0.04	51
23	0.24	52
24	0.43	53
25	0.63	55
26	0.83	56
27	1.02	58
28	1.22	59
29	1.42	61
30	1.62	62
31	1.83	64
32	2.04	65
33	2.26	67
34	2.48	69
35	2.71	70
36	2.96	72
37	3.21	74
38	3.50	76
39	3.81	79
40	4.16	81
41	4.56	84
42	5.05	88
43	5.69	93
44	6.51	100

Table 13: Initial 100-item of the Participation Measurement questionnaire and reasons of items deletion

	Items	Reason of deletion
01	participate in foods preparing at home	Misfit
02	move around by public transit bus	Disordered thresholds
03	remember past events in my life	
04	understand the rules of a new game	Disordered thresholds
05	trust myself	
06	tell a tale	Misfit
07	make a simple mental arithmetic (e.g. 10 + 10)	
08	understand a gesture of goodbye	
09	express myself clearly on the phone	Misfit
10	participate in collective games that I used to play previously	Disordered thresholds
11	choose my occupations based on priorities	
12	move around by taxi car	Misfit
13	work under pressure	Misfit
14	participate in a new game	Disordered thresholds
15	help people to find a solution to a crisis	
16	go to the hospital for care	
17	have hope in my future	
18	listen to music	Disordered thresholds
19	make a complex mental calculations (e.g. 100 - 17-14)	Misfit
20	understand a gesture of request of silence	Misfit
21	follow a TV program	Misfit
22	read a news paper	Disordered thresholds
23	go shopping (in a market, in a store etc.)	Disordered thresholds
24	speak to an audience	
25	follow my doctor's advice	Misfit
26	clearly understand ideas of others	
27	have respect for others	Misfit
28	tell the time	Misfit
29	understand your interlocutors on the phone	Misfit
30	participate in the maintenance of my home	Misfit
31	Send letters or postcards to relatives / friends	Disordered thresholds
32	follow a radio program	Misfit
33	make new friends	Misfit
34	trust my entourage	Misfit

35	go to my workplace	Disordered thresholds
36	express my gratitude to someone	
37	plan my time to prevent delays to appointments	Misfit
38	choose my business based on my physical abilities	
39	move around by « taxi moto »	Misfit
40	choose clothing appropriate to the climate	
41	take my medication	Misfit
42	interrupt a love relationship	Disordered thresholds
43	do my prayers	Misfit
44	verbally exchange with my entourage	Misfit
45	maintain my friendships	Misfit
46	have a balanced and varied diet	
47	express my ideas clearly	Misfit
48	participate in cultural festivals	Disordered thresholds
49	understand a gesture ordering to come	Disordered thresholds
50	communicate by "Short Message Service" (SMS)	Disordered thresholds
51	participate in the maintenance of furniture and other objects from my house	Misfit
52	keep my parental authority	Misfit
53	interrupt my professional activity	Disordered thresholds
54	participate in caring for my pets	Disordered thresholds
55	clearly understand the content of a letter	
56	go to worship places	Disordered thresholds
57	know how to express my disagreements in a proper way	
58	drink a drink in a café	Disordered thresholds
59	verbally exchange with a stranger	Misfit
60	follow the advice of my traditional therapist	Disordered thresholds
61	maintain my family relationships	Misfit
62	participate in the maintenance of my technical assistive devices (wheelchair, cane, etc.)	Disordered thresholds
63	keep my job	Disordered thresholds
64	properly choose the necessary condiments for dishes	Misfit
65	share my emotions with my entourage	Misfit
66	have a clean physical appearance	
67	involve myself in the decisions making of my entourage	
68	participate in caring for my children or grandchildren	
69	have a domicile	Disordered thresholds
70	ask for help in an emergency	Misfit

71	have good relationships with my colleagues	Misfit
72	have an emotional life	Misfit
73	do my rituals	Disordered thresholds
74	engage myself in a neighborhood association	
75	hire employees	Disordered thresholds
76	keep my accounts	
77	get involved in solving family problems	Misfit
78	dismiss an employee	Misfit
79	have sexual relations	Misfit
80	be tolerant	Misfit
81	attend weddings	Misfit
82	counting banknotes	Misfit
83	find a job	Disordered thresholds
84	engage myself in a religious association	Disordered thresholds
85	occupy a position of responsibility at work	Misfit
86	eat out	Disordered thresholds
87	participate in religious feasts	
88	militate in a political party	Misfit
89	engage myself in a volunteer work	Disordered thresholds
90	attend funeral	Misfit
91	occupy a position of responsibility in my religion organization	
92	engage myself in an ethnic association	Misfit
93	undertake a new professional activity	Disordered thresholds
94	militate in a union association	Misfit
95	keep cheerful	Misfit
96	give the account properly	Disordered thresholds
97	wear clean clothes	Misfit
98	maintain my employees	Disordered thresholds
99	ensure an electoral mandate	Disordered thresholds
100	stop professional contacts after a mutation	Disordered thresholds

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