"Satisfaction with activity and participation in patients with stroke"

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Abstract
Stroke is the most common cause of severe adult disability in the western world (Greenwood et al. 2009) and a major health problem all over the world (Kendall et al. 2007; Proot et al. 2002; Wade et al. 1987; Yu-Ying et al. 2002). In Belgium, the incidence of stroke is estimated at 2.62 per 1000 persons (Buntinx et al. 2002). Stroke may affect the social roles of the patient and it is therefore important to take into account the concept of social participation and the environmental and personal factors which may facilitate or hinder the fulfillment of the patients' social roles (Clarke et al. 1999). In the last decade, the International Classification of Functioning, Disability and Health (ICF, 2001) model, developed by the WHO (World Health Organization 2001) shows the interaction of personal factors (e.g. age, gender, education) and environmental factors (e.g. physical, social, attitudinal obstacles/facilitators) and their impact on body functions/structures, activities, and part...
SATISFACTION WITH ACTIVITY AND PARTICIPATION IN PATIENTS WITH STROKE

Thèse présentée en vue de l’obtention du grade de Docteur en Sciences de la Motricité

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Mai 2011
Il est prouvé que fêter les anniversaires est bon pour la santé. Les statistiques montrent que les personnes qui en fêtent le plus deviennent les plus vieilles.

Den Hartog
Thesis University of Groningen
Remerciements


Tout au long de ces années, il m’a été permis de rencontrer de nombreuses personnes. C’est ainsi que je tiens à remercier la Pr Detrembleur Christine qui a toujours été très attentive à l’évolution de ce travail et n’a jamais hésité à faire part de son expérience lorsque la situation l’exigeait.

Mes premiers pas dans la recherche scientifique ont donc été guidés par le Professeur Jean-Louis Thonnard et le Dr Carlyne Arnould qui, tous deux, m’ont inculqués leurs soucis constants de rigueur et de qualité.

Le Professeur Jean-Louis Thonnard, promoteur de cette thèse, m’a permis d’accéder au monde de la recherche scientifique alors que je n’avais aucune expérience réelle dans ce domaine. Il a accepté de patronner ce travail avec exigence et pertinence sans jamais faillir à son rôle de promoteur. Je lui en serai toujours reconnaissant.
Le Dr Carlyne Arnould (Haute École Louvain en Hainaut), co promotrice de cœur de cette thèse, a partagé sa rigueur scientifique et sa connaissance très pointue du modèle de Rasch. Sa clairvoyance et ses réflexions critiques ont été une aide très précieuse tout au long de ce travail. Je la remercie également pour son infaillible disponibilité et son sens pratique amenant souvent des solutions simples aux problèmes complexes. L’amitié et les connaissances du Professeur Jean-Louis Thonnard et du Dr Arnould Carlyne furent sans conteste les piliers de mon travail. Qu’ils trouvent ici le témoignage de ma reconnaissance et de mon amitié.

Je tiens également à remercier les Professeurs Xavier Sturbois (UCL-READ), Léon Plaghki (UCL-READ), Philippe Hanson (UCL Mont-Godinne), Jacques Grégoire (UCL-PSED) et le Dr Massimo Penta de m’avoir encadré tout au long de cette thèse et d’avoir cru en l’achèvement de ce travail. Je tiens, de même, à remercier le Dr Johanne Desrosiers (Sherbrooke Geriatric University Institute, Québec) d’avoir accepté de participer au jury de cette thèse. Leurs critiques constructives et leurs conseils m’ont aidé dans la finalisation de ce travail. Qu’ils sachent combien j’ai apprécié leurs regards avertis et à quel point je suis honoré de leur présence dans ce jury.

Je voudrais également associer à ces remerciements Madame De Limbourg Damienne, secrétaire de l’« Unité Réad », qui a toujours fait montrer d’une grande disponibilité et d’une serviabilité exemplaires. De même, je remercie l’ensemble des membres du secrétariat de la Faculté des Sciences de la Motricité qui, tout au long des années, sont restés très attentifs quant au respect des procédures administratives indispensables à l’achèvement d’un tel travail.

Cette thèse n’aurait pas été possible sans la collaboration enthousiaste des patients ayant participé aux expériences de ce travail. Qu’ils trouvent ici le
témoignage de ma sincère gratitude. Je tiens également à remercier le Dr André Peeters de m’avoir autorisé à recruter les patients dans son service (Stroke Unit – Cliniques universitaires St Luc, Bruxelles), la Haute École Louvain en Hainaut et en particulier son directeur Jean-Lambert Charlier de m’avoir donné la disponibilité nécessaire à la réalisation d’un tel travail.

Je voudrais aussi remercier tous mes collègues de l’Unité de Réadaptation et de Médecine Physique pour leur soutien et leur amitié. L’entraide et la bonne humeur de Yannick, Céline, Laure, Olivier, Caroline, Frédéric, Thibaut, Philippe, Delphine, Sébiyo - pour ne citer qu’eux – qui ont fait du laboratoire de Réadaptation un lieu de convivialité, d’épanouissement professionnel et humain.

Que tous trouvent ici l’expression de mon amitié.

Enfin, ma famille et mes amis qui m’ont apporté le soutien nécessaire à une telle entreprise. Je les en remercie. Merci plus particulièrement à mon épouse, Anne, et à mes enfants, Christelle et Stéphanie, qui ont subi mon indisponibilité récurrente durant de nombreuses années. Leurs encouragements, leur patience, et leur soutien indéfectible m’ont rendu la tâche plus facile. Qu’il trouve ici l’expression de toute ma gratitude et de mon affection.
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Introduction

Cerebrovascular accident (CVA), stroke, or “brain attack” refers to an acute onset of neurologic deficit lasting more than 24 hours or culminating in death caused by a sudden impairment of cerebral circulation (RaschWarlow et al. 2003). Stroke is the most common cause of severe adult disability in the western world (Greenwood et al. 2009) and a major health problem all over the world (Kendall et al. 2007; Proot et al. 2002; Wade et al. 1987; Yu-Ying et al. 2002). Consequently, stroke has potentially enormous emotional and socioeconomic impacts for patients, their families and health services, and the society (World Health Organization 2000). In Belgium, the incidence of stroke is estimated at 2.62 per 1000 persons (Buntinx et al. 2002).

Stroke is subclassified into ischemic and hemorrhagic types, based on the underlying pathogenesis. Eighty-five percent of CVA are ischemic in nature and involve the occlusion of a cerebral vessel with subsequent brain ischemia and infarction distally to the site of obstruction. Ischemic CVA may be caused by either atherosclerotic thrombi or distant emboli (Felberg et al. 2003; Kelley et al. 2003). Ischemic embolics are classified into arterial, cardioembolic, and cryptogenic subtypes, depending on the site of embolic origin (Smith et al. 2001). Cryptogenic CVA refers to cerebrovascular events in which the source of occlusive emboli remains unknown (Smith et al. 2001).
About two-thirds of patients survive a stroke, most with some degree of disability (Ellis-Hill et al. 2000). Clinical manifestations of stroke vary, depending on the site and size of the brain lesion. Patients with stroke present various physical and neuropsychological impairments such as motor, speech, visual, cognitive and perceptual disorders. Recovery from stroke can be seen as the return to the life the patients lived before their stroke and is often defined in terms of physical improvement (Doolittle 1992; Duncan et al. 1997). However, stroke may also affect the social roles of the patient. It is therefore important to take into account the concept of social participation and the environmental and personal factors which may facilitate or hinder the fulfillment of the patients’ social roles (Clarke et al. 1999). The concept of participation in society introduces a larger view of the stroke study (Hammel et al. 2008).

**International Classification of Handicap**

The International Classification of Functioning, Disability, and Health (ICF, 2001) model was developed in 2001 by the World Health Organization (WHO). In the last decade, this model has gained worldwide acceptance among rehabilitation health researchers and practitioners as a biopsychosocial framework than can be used to support a systematic approach for understanding chronic illness and disability across diverse populations and cultures (Peterson et al. 2005; World Health Organization
The overall intent of the ICF classification is to provide a standard language of health domains to be used for the description of health-related states (World Health Organization 2001). The ICF paradigm is structured around the following broad components: (a) body functions and structures, (b) activities (related to tasks and actions by an individual) and participation (involvement in a life situation), and (c) environmental and personal characteristic factors (Fig. 1).

The framework shows the interaction of personal factors (e.g., age, gender, education) and environmental factors (e.g., physical, social, attitudinal obstacles/facilitators) and their impact on body functions/structures, activities, and participation. In Figure 1, the double arrows depict the bidirectional interaction among the framework components. The arrows indicate that changes in one dimension have the
potential to influence and modify the other dimensions, although not always in a predictable unequivocal relationship.

The ICF is based on an interactive model of disability. “Disability” is not seen as an intrinsic feature of the individual, but as a result of interactions in an environment. The interaction of the same person with a health condition may yield different levels of functioning in different environments (Fougeyrollas 2002). Disability is viewed as the outcome of the interaction between an individual health condition and barriers in the environment (Hurst 2003; Schneidert et al. 2003; World Health Organization 2001). Environmental factors interact with the other ICF components of body functions/structures, activities, participation, and personal factors and can improve or impede the individual’s function in these three perspectives.

The ICF is not an assessment or a measurement tool, but rather a framework and a set of classifications on which assessment and measurement tools can be based. This distinction is sometimes misunderstood. The ICF provides a single list of activity and participation domains; it has been criticized for not clearly operationalizing the construct of participation in its framework (Barnes et al. 2010). The activity and participation dimensions require more attention because of their positions in the model. Activity is defined as the execution of a task or action by an individual, and participation is defined as involvement in a life situation (World Health Organization 2001).

Activities reflect relatively simple physical tasks or activities (e.g. “reaching objects in your near place”) that an adult does (Jette et al. 2003).
In contrast, the behaviors contained within the participation domain refer to much more complex categories of life behaviors (e.g. “Participating in leisure activities”) that only can be accomplished if a variety of tasks or component actions are used. In other words, the capacity to walk 10 m, for example, refers to activity, whereas walking in one's environment while performing daily activities refers to participation (Levasseur et al. 2008). Therefore, participation is the result of dynamic and complex interactions between a person (i.e., body functions and structures, capacity to perform activities, and other characteristics such as age, sex, culture, etc.) and his or her physical and social environment (Fougeyrollas 1995; Jonsson et al. 1999).

The ICF model is not the only model allowing a systemic approach for the understanding of chronic illness and disability. In the 1990s, Fougeyrollas and his Quebecer’s team developed the Disability Creation Process (DCP) (Fig. 2), an explicative model of the causes and consequences of diseases, trauma, and other disruptions to a person’s integrity and development (Fougeyrollas et al. 1998b). The DCP is based on an anthropological model of human development and disability (Fougeyrollas et al. 1998a); it maintains that the disability process is not independent of the dynamic and interactive processes between personal (intrinsic) factors and environmental (extrinsic) factors (Levasseur et al. 2007). These processes determine the situational result of the performance of life habits, where life habits are defined as daily activities (e.g., personal care and mobility) and social roles (e.g., interpersonal relationships and leisure) that are valued by the person or his sociocultural environment (Fougeyrollas et al. 1998b). The influence of the anthropological model is
reflected in the importance of environmental factors in the definition of participation: social participation is considered to be the outcome of the interaction between the individual and his or her environment (Fougeyrollas et al. 1998b; Fougeyrollas et al. 1998a). Personal factors, social participation, and the environment are conceptually distinct (i.e., mutually exclusive nomenclatures) (Levasseur et al. 2007).

In contrast, the ICF is based on the integration of two opposing models: the medical model and the social model (World Health Organization 2001). The medical model views disability as a problem of the person that is directly caused by disease, trauma, or other health conditions. In the social model, participation restriction is viewed mainly as a socially created problem and as a matter of the full integration of individuals into society (World Health Organization 2001). Participation restriction is not an attribute of an individual, but rather is a complex collection of conditions, many of which are created by the social environment (Levasseur et al. 2007).

To capture the integration of the various perspectives of functioning, the ICF uses a biopsychosocial approach and attempts to provide a coherent view of the different perspectives of health from biological, individual, and social perspectives. Thus, the definition of participation in the ICF is influenced by the medical and social models (Levasseur et al. 2007). Finally, capabilities and social participation in the DCP are two operationally distinct components, while in the ICF the same domains may correspond to activities and participation.
According to the DCP model, the impact of stroke is that it affects personal factors that include both impairment and disability. The characteristics of the person's environment also affect social participation after stroke. Social environmental factors include elements such as support from the family and utilization of health and social services, whereas physical environmental factors refer to natural or technical elements (e.g., climate, technical aids). As obstacles or facilitators, these factors can either hinder or help in the accomplishment of daily activities and social roles (Vincent et al. 2007). Because the concept of participation is quite similar in the DCP and the ICF classification models, we shall use the latter throughout this thesis.
The impact of stroke in the ICF model is illustrated in Figure 3 according to the three dimensions of functioning and disability. The brain lesions (e.g., cerebral artery occlusions) that develop during stroke may affect other body structures, such as the trunk, upper and lower limbs, and their components (e.g., muscles, joints), as well as several body functions. Depending on the location and the degree of cerebral damage, physical, cognitive, and affective functions may be impaired (Proot et al. 2002). Upper and lower limb functions are frequently impaired and constitute the main problem in many patients with stroke (Ashburn 1997; Desrosiers et al. 2003). Physical impairment refers to deficits in sensorimotor skills, such as a reduction in mobility (e.g., passive and active range of motion), a lack of control in rapid coordinated movements (e.g., gross manual and fine finger dexterity), or an exaggeration in muscular tone (e.g., spasticity). Hand sensory impairments may be observed, for example in tactile pressure detection, tactile spatial resolution (i.e., perception of spatial features of objects and surfaces), thermal sensation, or proprioception (i.e., position and movement sense of hand or fingers). Cognitive impairment can affect the memory so as to impair the activities of daily living (ADLs). Moreover, some patients with stroke can develop dementia within 12 months after stroke (Barba et al. 2002; Claesson et al. 2005; Desmond et al. 2000). Affective impairment refer to psychological changes like depression and anxiety following stroke (Hafsteinsdottir et al. 1997).
Figure 3: Impact of stroke on the patient with stroke functioning according to the ICF dimensions (modified from WHO 2001).
Stroke also may limit the achievement of daily activities, leading to disability. These limitations refer to deficits in the execution of tasks that require the use of the upper limbs (e.g., eating, drinking, grooming, dressing, and managing daily routine or executing several tasks) or lower limbs (e.g., walking, running, climbing) (Desrosiers et al. 2003). Accumulating evidence suggests that assessments of neurological functions and activity limitations are insufficient to evaluate the total influence of a stroke on a patient’s experiences (Suenkeler et al. 2002; Testa et al. 1996).

Finally, stroke may restrict the patient’s participation in different life situations, daily living, and leisure activities. Participation restrictions represent the problems that the patient experiences in the fulfillment of social roles that are regarded as normal considering his/her age, sex, and the society and culture in which he/she lives (Fougeyrollas et al. 1998b). For example, the social roles of a stroke patient may include being a spouse, brother/sister, colleague, or friend; visiting a museum; going to the cinema; and travelling by train or by plane. Through participation in daily occupations, individuals acquire skills and competencies that are vital for human development and are important determinants of health and well-being (Law et al. 1998; Wilcock et al. 1998a). Participation restrictions may include difficulties in caring for his/her spouse or children, in performing housework, and in communicating and having good relationships with his/her peers.

The three dimensions of functioning also may be influenced by contextual environmental or personal factors that represent the background of the patient’s life. Environmental factors are the external features of the
Environmental and personal factors can facilitate or hinder the patient's functioning at the body, individual, or social level. For instance, a low family income may prevent the patient from receiving treatments that are expensive but effective in reducing upper limb impairments; the use of assistive devices may reduce activity limitations; and the fear of attitudinal behavior may restrict the patient's participation.

Although considered to be an important concept, there is no consensus regarding the definition of social participation in the literature. While most authors define social participation as an individual's involvement in social activities (Levasseur et al. 2010), the concept has emerged in a new way from a recent qualitative study (Hammel et al. 2008). Participants with diverse activity limitations conceptualize participation as a group of values that includes:

- active and meaningful engagement,
- choice and control, access and opportunity,
- personal and societal responsibilities,
- supporting others, and
- social connections, inclusion, and membership.

Accordingly, participation not only includes active engagement in life situations at the societal level, but also refers to the personal meaning and satisfaction resulting from that engagement. The new challenge for future research is, therefore, to consider not only the level of participation achieved but also the patient’s satisfaction with participation (Hammel et al. 2008). It is important to consider the patient’s perspective and life experiences when establishing treatment goals; these aspects can be considered through satisfaction with social participation (Levasseur et al. 2010).

The satisfaction dimension may concern the interaction between all ICF dimensions, because living with disability requires constant adjustments and changes in a dynamic process between environmental factors and personal factors (Schwartz et al. 2007). Most patients with stroke are undergoing changes in their physical and psychological wellbeing. In this context, satisfaction can be viewed as the degree of congruence between the patient’s expectations and achievements relative to his/her quality of life (QoL) (Henley 1967; Sartorius 1987).

To understand the patient's functioning, in addition to the three dimensions of the ICF model, it is important to consider that the person requires autonomy to execute activities in real-life situations. Levasseur cites the Longman Dictionary of Contemporary English to define autonomy as the right of self-government or management of one’s own affairs (Levasseur et
Autonomy refers to the capacity to govern and regulate one’s own thoughts, feelings, and actions freely and responsibly. In other words, autonomy is a person’s capability to make choices and to direct his/her life in accordance with his/her own reason and goals (Proot et al. 1998). Concepts related to autonomy and control will be considered to understand the participation domain.

The control that a person has represents how and when things may be done in accordance with his/her wishes. This control allows a person to reach his/her personal goals (Perenboom et al. 2003), according to the ICF participation concept that involves life situations (World Health Organization 2001). Autonomy is the ability to decide and to achieve what a person wants to do, on the condition that the decision and action do not cause harm or ill-feeling to others or to society (Chan 2002). Two types of autonomy are typically distinguished: decisional autonomy, which is the ability to make decisions without external restraint or coercion (e.g., to dress oneself); and executional autonomy, which is the ability and freedom to act on the basis of decisional autonomy (e.g., dressing oneself as decided) (Chan 2002). Decisional autonomy is the more complex autonomy, as it depends on the cognitive and perceptual aspects of a person; however, both executional and decisional autonomies can be limited due to impairments in body functions or structures (Chan 2002).

Some authors have suggested that the concept of autonomy is not sufficiently captured within the ICF (Cardol et al. 2002b; Grimby 2002), even
though autonomy is a key concept for client-centered rehabilitation. One way to apprehend autonomy is to measure the patient’s satisfaction with his/her activity and participation. In most cases, a patient’s autonomy will be decreased after a stroke (Sim 1998).

Some questionnaires based on the conceptual model of the WHO are available, such as the Impact on Participation and Autonomy Questionnaire (IPAQ) (Cardol 1999), the Participation Measure for Post-Acute Care (PM-PAC) (Gandek et al. 2007), and the Late-life Function and Disability Instrument (Late-life FDI) (Jette et al. 2002). To our knowledge, few tools have been developed in French to measure the participation domain of the ICF, except for the IPAC and the PM-PAC, which were recently translated by Poulin and Desrosiers (Poulin et al. 2010). Similarly, few tools allow the measurement of satisfaction, aside from the Assessment of the Life Habits (LIFE-H) (Fougeyrollas et al. 1998b). LIFE-H was developed specifically to measure the social participation of people with disabilities according to the Quebec Classification. This tool is based on two specific elements: the level of difficulty in executing life habits in the person’s actual environment, and the type of assistance required to execute these habits (technical assistance, physical arrangements, and human assistance). This tool is an operationalization of social participation and proposes a satisfaction scale that is not involved in the scoring of the social participation.
Satisfaction and its measurement

The concept of satisfaction is very complex, involving cultural, sociodemographic, cognitive, and affective components (Aharony et al. 1993). Some time ago, Henley (1967) stated that: “general satisfaction is a perceived state of mind that reflects relative contentment and freedom from anxiety, and is reportable, qualitatively, by patients” (Henley 1967). The interest of this definition consists in the awareness of the qualitative self-reporting of patients (Sitzia et al. 1997). Satisfaction corresponds to the person’s own perspective of his/her performance in activities and life situations that meet his/her needs; it should not necessarily be related to the difficulty in the performing of the activity or the life situation.

People living with activity limitations might have fewer opportunities to be satisfied with life or to experience happiness, which can have a negative effect on their QoL (Bränholm et al. 1991). Moreover, satisfaction (unlike body functions) cannot be measured directly with physical units. For instance, the Newton unit can be used to measure the grip strength of a stroke patient or the force exerted by a cyclist on the pedals of a bike and allows them to be compared quantitatively. Instruments using physical units to measure body functions allow quantitative comparisons to be made across people and over time, provided that the testing procedure supplies reproducible measures. Physical measures obtained by such instruments satisfy the requirements of an objective measurement, as defined by the Institute for Objective Measurement (IOM) (Institute for Objective
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Measurement 2000): “objective measurement is 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 and no matter who or what relevant person or thing is measured”.

Because satisfaction is subjective, the patient’s self-report has been described as a valid measure of a patient’s experience of satisfaction (Simon et al. 2003). The measurement of satisfaction with activity and participation is important to determine the complete impact of CVA on a patient’s functioning. This measurement should provide health professionals with the information required to identify the patient’s needs, to plan and implement interventions, to assess the effectiveness of the interventions, and, if necessary, to adjust the interventions. Consequently, it is essential to have high-quality measurements. Instruments assess the degree of patient performance in activities and life situations, the required assistance, or the experienced difficulty. Most instruments focus on satisfaction with community services, health care, etc. (Pandora et al. 1999; Pound et al. 1994; Simon et al. 2003). Therefore, it would be useful to develop a new measure of satisfaction with activity and participation for patients with stroke.

Satisfaction as a construct is observed indirectly through the achievement of activities and life situations. Satisfaction is a latent variable concealed within a person in the same manner as pain or anxiety (Rasch 1960; Thurstone 1959). Satisfaction can be measured by eliciting the patient’s perceived satisfaction with life situations by using a questionnaire with ordered categories. Questionnaires generate ordinal data that have no
metric properties, because they rely on counts of potentially unequal units. The measurement of satisfaction is possible through the performance of selected activities and life situations, and is based on the general idea that any measurement implies the conceptualization of an underlying continuum representing the variable that is being measured (Rasch 1960; Thurstone 1959).

For instance, when measuring the length of an object, we refer to a continuum that is only partially represented by the ruler actually used. The obtained measure is generally represented as a point along the ruler, and its location indicates the “amount” of length. Satisfaction can also be conceptualized as a continuum representing infinite levels from “least satisfied” to “most satisfied”. Measuring the satisfaction of a stroke patient with his/her activity and participation is equivalent to determining the stroke patient’s location along an underlying scale of satisfaction. This measurement scale can be materialized by situations or activities, called “items”, which require some amount of satisfaction to be satisfactory. Although there may be an indefinitely large number of activities and life situations, only a sample of activities and life situations are included in a test or questionnaire.

The items selected in a questionnaire are the operational definition of the variable (i.e., the graduations of the measurement scale). Therefore, it is important that they cover the whole range of satisfaction that one wants to explore. As illustrated in Figure 4, the more satisfactory an item is, the smaller the satisfaction level it
requires to be performed and *vice versa*. Performance of the less satisfactory items is perceived as satisfying only by the more satisfied patients, while performance of the more satisfactory items can also be perceived as satisfying by the less satisfied patients. For instance, patient A presents a very low satisfaction level because he/she is expected to perceive only the three least satisfactory items as satisfying; patient B has an intermediate satisfaction level that should enable him/her to perceive approximately half of the items as satisfying; and patient C has the highest satisfaction level and is supposed to estimate the least satisfactory item as satisfying.

Figure 4: Representation of the satisfaction continuum. Thick lines indicate, from left to right, the location of activities and life situations (or items) of decreasing satisfactory level. Arrows indicate the location of patients A, B, and C on the satisfaction continuum.

Thus, the measurement of a latent variable such as satisfaction starts with the counting of the number of items “succeeded” (i.e., perceived as satisfying). This measurement process can be applied regardless of the response format of the questionnaire used to record the responses. The
dichotomous response format (e.g., satisfied or dissatisfied) is the simplest format because it includes only two response categories (e.g., the patient with stroke is satisfied or dissatisfied with performing each activity and life situation). The polytomous response format allows more subtle responses, because it includes more than two ordered categories (e.g., each activity and life situation is scored as either “very dissatisfied”, “dissatisfied”, “satisfied”, or “very satisfied”).

The operational definition of the satisfaction continuum occurs differently depending on the response format used. In the dichotomous response format (see Figure 5), the “graduations” of the underlying satisfaction level scale are the item satisfactory locations. The satisfactory location is defined as the level of satisfaction that gives an equal chance of the patient’s being satisfied or dissatisfied, and it is the threshold between the “dissatisfaction” and “satisfaction” categories. In the polytomous response format (see Figure 6), the graduations of the measurement scale are the item threshold locations defined between successive response categories. The threshold of each item corresponds to the satisfaction level required to have an equal probability of endorsing a response rather than the previous one. Note that the item satisfactory level merely represents the average value of its encompassed thresholds.
Figure 5. Dichotomous response format. The satisfaction continuum is materialized by the item satisfactory level (thick line; $\delta_i$). Patients with a satisfaction level lower than the item satisfactory level (i.e., located to the left of the item) are expected to be dissatisfied; patients with a satisfaction level higher than the item satisfactory level (i.e., located to the right of the item) are expected to be satisfied.

Figure 6. Polytomous response format. The satisfaction continuum is materialized by the item thresholds (thick lines). The first threshold ($\tau_1$) is located at the satisfaction level required to respond “dissatisfied” rather than “very dissatisfied” while the second threshold ($\tau_2$) is located at the satisfaction level required to respond “satisfied” rather than “dissatisfied” and the third threshold ($\tau_3$) is located at the satisfaction level required to respond “very satisfied” rather than “satisfied”. The item satisfactory level (arrow; $\delta_i$) represents the average value of its encompassed thresholds. Patients with a satisfaction lower than the first threshold are expected to be very dissatisfied in performing the activity or the life situation; patients with a satisfaction located between the first and the second thresholds are expected to be dissatisfied in performing the activity or the life situation; Patients with a satisfaction level located between the second and the third threshold are expected to be satisfied and patients with a satisfaction level higher than the third threshold are expected to be very satisfied in performing the activity or the life situation.
Whatever the response format used, a score is assigned to each response category in such a way that the higher scores represent higher satisfaction levels (e.g., in the dichotomous response format: 0 = dissatisfied, 1 = satisfied; in the polytomous response format: 0 = very dissatisfied, 1 = dissatisfied, 2 = satisfied, 3 = very satisfied). A total score is computed by summing the patient’s scores to each item. If the successive response categories really represent increasing levels of satisfaction as postulated a priori, then the “amount” of satisfaction that a patient possesses can be inferred from his/her total score: the higher the total score, the higher the satisfaction level with activity and participation.

The total score is not sufficient to make quantitative comparisons, because a unit progression in total score does not necessarily entail the same progression in satisfaction throughout the continuum. Such comparisons require a measurement unit that is constant and reproducible throughout the range of the variable measured (Merbitz 1989; Wright 1997). Therefore, measurement models are required to translate the ordinal total score observed in a questionnaire into a linear satisfaction measure.

The Rasch model

The Rasch model (Rasch 1960) belongs to the family of “Item Response Theory” (IRT) models that were developed to overcome the limitations of ordinal scales (Bertrand et al. 2004; Hobart et al. 2007). In the case of satisfaction, the IRT model is based on the assumption that subjects with a
higher perceived satisfaction level should have a higher probability, relative to subjects with a lower satisfaction level, to be satisfied with any item. In the same manner, items with a higher satisfactory level should have a high probability, relative to items requiring a lower satisfactory level, to be perceived as satisfying by any subject. The Rasch model is a probabilistic model that is prescriptive in the sense that it formulates the requirements of an objective measurement and allows one to verify if these requirements are satisfied in the observed data (Andrich 1989; Hobart 2002; Penta et al. 2005; Rasch 1960).

The Rasch model was developed by the Danish mathematician Georg Rasch in the 1960s to construct an intelligence scale. It was progressively and successfully applied to a large panel of sciences, such as psychology, sociology, educational sciences, medicine, and many other disciplines in the human sciences (Conrad et al. 2004). When applied to the domain of satisfaction, the model states that the probability of choosing any response category to an item only depends on the subject’s satisfaction and the satisfactory level in his/her activity and life situations. The model estimates the satisfactory level and subject’s satisfaction on a common linear scale (Rasch 1960). Originally built for dichotomous response formats, the Rasch model has evolved to comply with polytomous response formats (Andrich 1978b; Andrich 1979; Andrich 1978a; Masters et al. 1997), also called “rating scales” (Andrich 1978b; Andrich 1978a; Masters 1982). These models prescribe that the probability of endorsing any response category to an item solely depends on the subject satisfaction, the item satisfactory level, and the threshold satisfactory level.
This thesis will now briefly describe the basic psychometric qualities that are required to use the model, i.e., reliability, validity, unidimensionality and linearity, as well as invariance and ordered response.

**Reliability**

Reliability is a property that describes how consistent the instrument is (Frisbie 1989) and how reproducible the scores are. In the case of self-reporting scales, the same patient should provide the same responses twice (test-retest reliability).

**Validity**

Validity is defined as the ability of an instrument to actually measure what it purports to measure (Messick 1989). Specific objectivity implies that the subject measures are independent of the relative satisfactory level of the particular items used, and similarly, that the relative item satisfactory levels are independent of the satisfaction of the particular sample who answered them. The content of the instrument (e.g., items, scoring procedure, etc.) usually relies on expert judgments (content validity). The results of the instrument should coincide with results of another relevant test (concurrent validity), or, in the absence of a gold standard, with a widely used test that is theoretically related (construct validity).

A test has construct validity if it accurately measures a theoretical, nonobservable construct or trait. The construct validity of a test is determined over a period of time on the basis of an accumulation of evidence. There are numerous ways to establish construct validity. Two
Two methods of establishing a test’s construct validity are convergent/divergent validation and factor analysis, but in this study, we use only the convergent/divergent validity method. Convergent validity is concerned with “demonstrating that two independent methods for inferring an attribute lead to similar ends” (Nunnally et al. 1994). In practice, convergence is often demonstrated by examining the extent to which measures of the same or similar variables are correlated. The underlying assumption is that a measure accurately represents a variable if it correlates highly with other measures of the same or similar variable. Divergent validity is concerned with the extent to which a measure is novel in the sense of measuring something different from that provided by other measures. Divergence is thus concerned with empirically establishing a measure’s relative uniqueness. Divergent validity is evidenced when different attributes of theoretical interest are not correlated to an extremely high degree; that is, they share little common variance (Whitley Jr. 1996)

This property is essential to obtain measures that maintain their quantitative status regardless of the particular context in which they occur (Wright 1989). The length measure of an object is independent of which ruler is used and the calibration of a ruler is maintained irrespective of what it is measuring. Similarly, the subjects measured by a questionnaire must retain the same satisfaction regardless of the relative satisfactory level of the
particular items encountered and the items must maintain their satisfactory level regardless of the satisfaction of the respondent. This requirement is not satisfied when using the total scores of a questionnaire. Indeed, the total score of a subject depends on the satisfactory level of the particular items used in the questionnaire (Rasch 1960). It will be high if the questionnaire includes many items with very satisfactory levels and will be low if the questionnaire includes a great proportion of items with low satisfactory levels although the subject’s satisfaction has remained the same. The total score which may be computed for each item also depends on the satisfaction level of the particular sample used (Rasch 1960).

**Unidimensionality**

Unidimensionality of an instrument is met when it measures only one variable without being influenced by other factors (e.g., gender, language community, residence, etc.). In the case of satisfaction measurement, no other attribute of the subjects or the items than satisfaction is theorized to account for the probability of endorsing a response. This requirement called “unidimensionality” is essential to achieve an objective measurement as found in physical sciences (Andrich 1988; Bond et al. 2007; Wright 1989). For instance, a ruler measures only the length of the objects and should not be biased by other attributes such as its temperature, weight, volume, texture, or color. Similarly, the items of a questionnaire intended to measure satisfaction should provide a measure only related to satisfaction of the subject, unbiased by other attributes of the subject or of the items.
Actually, unidimensionality is a theoretical concept which is never entirely met in practice as the complete isolation of one attribute from the others is extremely difficult (Andrich 1988). However, getting as close as possible to this ideal is necessary required to obtain a measurement scale which allows the same attribute (e.g. satisfaction) to be quantitatively compared across different subjects (Wright 1989). The metric requirement of unidimensionality may be considered to be met when the responses to the items are influenced in a dominant way by the latent variable purported to be measured (Hambleton 1991). Rasch analysis can be used to verify the extent to which the responses of each subject to each item fit the requirement of unidimensionality (Andrich 1988). The observed responses are contrasted with the responses expected by the model which formulates this requirement. The degree of similarity between observed and expected responses is reported through different fit statistics and indicates the extent to which unidimensionality is satisfied in the observed data (Andrich 1988; Rasch 1960; Smith 2000; Smith 1998; Wright 1982; Wright 1969; Wright 1979).

**Linearity**

Once the observed responses fit the model’s prescriptions, the Rasch model estimates the satisfaction level of each subject and the satisfactory level of each item or threshold on a common linear interval scale (Rasch 1960). Moreover, the location of each subject is estimated independently of the relative satisfactory of the particular item set used to collect the responses and, similarly, the location of each item (or threshold) is estimated...
independently of the satisfaction of the particular sample assessed (Rasch 1960). These two properties known as the “linearity” and the “specific objectivity” are essential to obtain objective measures like those found in physical sciences (Andrich 2004; Bond & Fox 2007; Hobart 2002; Wright 1979).

Linearity implies that the unit of the measurement scale is constant throughout the scale so that identical intervals represent the same amount of the variable purported to be measured (Wright 1989). Linearity is not obtained when we work with ordinal total scores (Merbitz 1989; Wright 1997; Wright 1989). Indeed, the use of raw total scores has several limitations especially when quantitative comparisons are made across subjects or over time. Firstly, the ordinal scores assigned to the response categories of polytomous items are separated by unknown distances (Merbitz 1989; Wright 1989). To illustrate, imagine a questionnaire measuring satisfaction level on the four-level scale: (0) very dissatisfied, (1) dissatisfied, (2) satisfied and (3) very satisfied. It is impossible to know a priori if responding “dissatisfied” rather than “very dissatisfied” to a given item represents the same progress in satisfaction level than responding “satisfied” rather than “dissatisfied” although the score has increased by one point in both cases. Similarly, a progression from “very dissatisfied” (scored as 0) to “very satisfied” (scored as 3) represents greater progress than from “very dissatisfied” (scored as 0) to “dissatisfied” (scored as 1), but not necessarily a three-fold progress. Consequently, the total scores allow subjects’ satisfaction to be compared in terms of “higher than”, “lower than” or “equal to”, but they fail in determining “how much higher” or “how much lower”.

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Secondly, obtaining the same score to different items does not necessarily represent the same amount of the latent variable (Bond & Fox 2007; Penta et al. 2005). The relative satisfactory of the item must therefore be taken into account before the total scores can be converted into linear measures and quantitative comparisons be made. The Rasch model uses a logistic transformation to convert the ordinal total scores into linear measures expressed in “logits” (i.e., log-odds units). The logit is a probabilistic unit defined as the natural logarithm of the odds of being satisfied (i.e., the satisfied/unsatisfied probability ratio) of a subject to an item. This unit is constant throughout the measurement scale. At any level of the measurement scale, a 1-logit difference between two subjects indicates that their odds of being satisfied with performance in a given activity or life situation 2.71:1 (i.e. e^{1}:1); a 2-logit difference indicates 7.39:1 odds (i.e. e^{2}:1), and so on. Consequently, the measures obtained by the Rasch model are linear; they can be used to quantitatively compare the satisfaction of different subjects or to follow their satisfaction over time.

**Invariance**

Fit statistic analyses are particularly useful during the construction of a questionnaire to select the items that line up on a unidimensional continuum. Provided that the data fit the requirement of unidimensionality, the scores observed to any particular item should not be influenced by other factors of the subjects than just the variable of interest. Hence, subjects of the same satisfaction should obtain the same score to any item, regardless of their other characteristics (e.g., age, gender, handedness). If this is not the case,
the item is biased or, according to a more recent terminology, the item presents a differential functioning (Holland 1993). The Rasch model allows the invariance of the item functioning to be tested across various subgroups of subjects using differential item functioning tests (Andrich 2004; Smith 1992; Wright 1979). The invariance principle requires that the relative satisfactory level of the items should remain stable across the two substantially different subsamples (within the constraints of the requirement for targeting items and persons). Differential Item Functioning (DIF) studies a failure in the invariance principle. DIF investigates the items in a test, one at a time, for signs of interactions with sample characteristics. Differential item functioning methods are used to evaluate whether different subgroups respond differently to particular items within a scale, after controlling for group differences. The satisfaction levels are usually determined by the total scores on the test. In this way, the DIF analysis for one item is as independent as possible of the DIF analyses of the other items.

Due to its specific logistic formulation, the Rasch model transforms the total score of each subject into a measure independent of the relative satisfactory level of the particular items considered and, similarly, it transforms the total score of each item into a measure independent of the satisfaction level of the particular sample considered. This is possible because the Rasch model defines the relative item satisfactory level that is the difference between item satisfactory levels that is invariant. Then, by fixing an arbitrary origin, the person measures can be estimated independently of the satisfactory level of the particular items encountered. There is currently no other mathematical formulation that allows the subject
measures and the item satisfactory levels to be estimated independently of
one another (Wright 1979). That's why the Rasch model is the only model to
date that approximates objective measurement in health sciences provided
that the observed data fit the model's requirements (Rasch 1960).

Ordered response categories

The methods allowing the goodness of fit to be quantified can be
applied to both dichotomous and polytomous response formats. A
supplementary verification is however required in the case of polytomous
items. When constructing a polytomous rating scale, a score is assigned to
each response category so that higher scores represent a higher amount of
the variable purported to be measured, for instance: (0) very dissatisfied, (1)
dissatisfied, (2) satisfied and (3) very satisfied. The order of the response
categories is postulated a priori based on the common sense that most
satisfied subjects have a higher satisfaction than a less satisfied subject, and
inversely. It is therefore important to examine whether or not the order of the
response categories postulated a priori is verified in the observed data
(Andrich 1996a). The Rasch model makes it possible to verify whether the
successive response categories of each item represent increasing levels of
satisfaction and whether the thresholds between successive response
categories are located on the continuum in the anticipated order (Andrich
1996b). When the thresholds are reversed, the rating scale does not function
as expected and the item presenting disordered thresholds is detected.
The specific purpose of this research

Status questionnaires are becoming increasingly popular as measurement instruments in the health studies. However, the psychometric properties of these instruments must be verified by using an adequate tool such as the Rasch model. The main purposes of the present work were (1) to develop a new scale, based on the Rasch model, for measuring stroke patients’ satisfaction with activity and participation; (2) to investigate the responsiveness of this scale; and (3) to study the relationship over time between body functions and activity with the perceived satisfaction of activity and participation.

Chapter 1 presents the development and validation of SATIS-Stroke, a Rasch-built measure of perceived satisfaction with activity and participation in patients with chronic stroke. The SATIS-Stroke questionnaire was submitted to about 100 patients with chronic stroke and resubmitted to the same patient group 1 month later. A Rasch analysis was performed to construct a linear and unidimensional scale. The invariance of SATIS-Stroke was examined through DIF tests. The satisfactory hierarchy of the 36 SATIS-Stroke activities and life situations was compared across various patient subgroups (age, gender, delay after CVA onset, home residence, CVA side, and marital status). Overall, the item satisfactory hierarchy was invariant across the various demographic and clinical subgroups of stroke patients. The validity and reproducibility of SATIS-Stroke was also assessed.
The development and validation of SATIS-Stroke are presented as they appeared in the *Journal of Rehabilitation Medicine*.

The construction of a new scale is not sufficient, even if it has psychometric properties such as validity or reliability. Self-reporting outcome measures by multi-item questionnaires require that users understand the meaning of the measurement results. As there is no consensus concerning how to investigate an instrument’s best sensitivity to change (Middel et al. 2002), responsiveness is considered as a necessary measurement property of instruments intended for application in evaluative studies measuring longitudinal changes in health (Beaton et al. 2001; Liang et al. 2002). Numerous approaches for evaluating responsiveness have been reviewed by various authors (Beaton et al. 2001; Liang 1995; Liang et al. 2002; Terwee et al. 2003; Wyrwich et al. 2000).

Responsiveness is described as the ability of an instrument to measure clinically important changes over time when change is present (Fitzpatrick et al. 1998). Responsiveness can be viewed as the longitudinal validity or as a measure of treatment effect (Terwee et al. 2003). Patient-reported health instruments have, by far, the greatest application in clinical trials, and most of the literature on responsiveness relates to the measurement of change in health for groups of patients (Fitzpatrick et al. 1998).

There are two broad approaches used to assess responsiveness: distribution-based and anchor-based (Norman et al. 2001; Wyrwich & Wolinsky 2000). Distribution-based approaches relate changes in instrument scores to some measure of variability, the most common method being the
effect size statistic. The three widely reported effect size statistics use the mean score change in the numerator, but have different denominators (Fitzpatrick et al. 1998). The effect size (ES) statistic uses the standard deviation of baseline scores (Liang 1995). The standardised responses mean (SRM) uses the standard deviation of the change score to incorporate the response variance in change scores. However, both ES and SRM may be influenced by natural variance in the underlying state and by measurement error. The modified standardised response mean (MSRM), or responsiveness index, addresses the inherent natural variance that may occur in patients who otherwise report their health as unchanged, as well as the nonspecific score change by using the standard deviation of change in patients who are defined as stable (Deyo et al. 1991). In demonstrating responsiveness to a clinically important change, instruments should detect change above the nonspecific change incorporated in the MSRM (Deyo et al. 1991).

It has been suggested that statistical measures of responsiveness are an insufficient basis for assessing responsiveness, and that patients’ views on the importance of the change should inform the evaluation process (Liang et al. 2002; Terwee et al. 2003). Anchor-based approaches assess the relationship between changes in instrument scores and an external variable (Norman et al. 2001). This external variable may include health transition items or global judgements of change used to estimate the Minimal Clinically Important Difference (MCID), the instrument change score corresponding to a small but important change (Jaeschke et al. 1989; Juniper et al. 2002). The MCID can inform sample size calculations, but consideration must be
given to specific groups of patients and settings (Terwee et al. 2003). Score interpretation may be improved through the provision of evidence relating to score variation (Terwee et al. 2003) or a score range against which real change may be assessed (Beaton et al. 2001).

External variables, including transition ratings, also have been compared to instrument score changes by using correlation. This form of longitudinal validity (Kirshner et al. 1985; Terwee et al. 2003) assesses the extent to which changes in instrument scores concord with an accepted measure of change in patient health (Deyo et al. 1991; Fitzpatrick et al. 1998).

The ability of an instrument to distinguish clearly and precisely between respondents relative to reported health or illness is referred to as precision (Fitzpatrick et al. 1998). Ideally, items within an instrument should capture the full range of health states to be measured and should support discrimination between respondents at clinically important levels of health (Fitzpatrick et al. 1998). Precision is influenced by several factors, including response categories and item coverage of the defined concept of health purportedly measured by the instrument. The use of limited response categories lacks precision and detail, whereas the inclusion of more gradations of response increases the measurement precision (Fitzpatrick et al. 1998).

Chapter 2 investigates the sensitivity to change of the SATIS-Stroke questionnaire. Stroke patients were followed for 6 months and were assessed three times at acute, postacute, and chronic phases. The SATIS-
Stroke questionnaire was able to assess changes over time in the satisfaction level of patients with stroke. This chapter is presented as it had appeared in *Journal of Rehabilitation Medicine*.

Chapter 3 investigates the relationships between the perceived satisfaction with activity and participation and the different ICF dimensions. The relationships between body functions, activity, environmental factors, and satisfaction with activity and participation were investigated in a sample of 45 patients at acute, postacute and chronic phases. The influence of the human and physical environmental factors was investigated at postacute and chronic phases. At the acute phase, no significant relationship was found between the perceived satisfaction measure and the different ICF dimensions. At the postacute phase, all ICF variables excepted mood status were enhanced, which indicates that the patients’ health status improved at the same time that the perceived satisfaction increased. Only manual ability was related significantly (albeit weakly) to the perceived satisfaction. At the chronic phase, only the depressed status was increased significantly compared with the postacute phase. Satisfaction was significantly related with all ICF variables, body functions (except the depressed status), manual and locomotion activities, and human aids. A linear regression showed that the manual ability and the body functions were the best predictors of satisfaction, but they explained only 43% of the variance. The SATIS-Stroke questionnaire successfully determined changes in satisfaction among stroke patients. Chapter 3 is presented as it was published in the *Archives of Physical Medicine and Rehabilitation*. 

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Chapter 1

SATIS-Stroke: A Satisfaction Measure of Activities and Participation in the actual environment experienced by chronic stroke patients

Abstract

Objective: To develop a satisfaction measure of activities and participation in the actual environment experienced by chronic stroke patients using the Rasch measurement model. Methods: The authors developed a 36-item questionnaire based on the ICF model and existing scales. The questionnaire was submitted to 101 patients (70% men; mean age, 63 years) without major intellectual deficits who live in different types of residences (homes and nursing homes). The questionnaire was resubmitted after 1 month.

The patients’ responses were analysed separately with the RUMM Rasch software to select items presenting an ordered rating scale, sharing the same discrimination, and fitting a unidimensional scale. Results: The final SATIS-Stroke scale consisted of 36 items rated by the patients. The patients reported perceptions over a wider range of measurement with high reliability (\(R = 0.94\)), and good reproducibility over time (ICC= 0.98). The SATIS-Stroke measures are significantly related to age and place of residence. Conclusions: SATIS-Stroke is a functional scale specifically developed to measure satisfaction with activities and participation, providing
goal-setting guidelines for treatment planning. Its range and measurement precision are appropriate for clinical practice.

Published as:
1.1. Introduction

Post-stroke hemiplegia is one of the most prevalent forms of motor disability, occurring in 1% of the population (Hankey 1999). Depending on the severity and the location of the brain lesion, stroke may affect various body functions and structures (body dimension), limit the accomplishment of daily activities (individual dimension), and restrict the subjects’ participation in familial and societal life (social dimension) (World Health Organization 2001). In the past, most instruments were developed to measure either the body dimension or the individual dimension according to a biomedical perspective of health, so neglecting the social dimension. Optimising a patient’s participation in society has recently become a major goal for the rehabilitation of patients with chronic disorders including chronic stroke patients.

Participation is defined in the International Classification of Functioning, Disability and Health (ICF, WHO-2001) as the patient’s involvement in life situations. Participation restrictions represent the problems the patient experiences in the fulfilment of social roles (e.g., being a spouse, parent, worker, or friend) that are regarded as common, considering his age, sex, and the society and culture in which he lives. On the contrary, activity is defined as the execution of a task or action by an individual. The activity and participation domains of the ICF are qualified by two qualifiers: capacity and performance. Capacity refers to an individual’s ability to execute activities in a non-actual standardized environment. Performance describes what an individual does in the actual environment in which he is living. Because the
actual environment includes a societal context, performance can also be understood as an "involvement in a life situation". Disregarding the social dimension may lead to inappropriate interventions in long-term rehabilitation, especially when patients return to the community (Cardol et al. 2001). In the ICF, activity and participation are expressed through the same list of situations and activities, called items. Several authors (Clapton 2002; Smith 2002a) have tried to clarify the concept of participation to differentiate participation from activity items. Contrary to the activity dimension, participation is not restricted to a limited environment (e.g., the hospital or home) but concerns a wider physical and social environment encompassing all possible life circumstances. Moreover, participation implies that the person is able to control his own life in every life situation, even if he cannot complete the activities himself (Perenboom & Chorus 2003). Participation is thereby the result of a dynamic and complex interaction between the person (i.e., body functions and structures, capacity to execute activities, and other characteristics such as age, sex, culture, etc.) and his physical and social environment (Fougeyrollas 1995). For example, a stroke patient who is able to move around with his wheelchair (no activity limitation) may be restricted when it comes to attending a play because there are no ramps into the building (participation restriction).

Several instruments have been developed to measure patients' activities and participation (Noreau et al. 2004) in chronic stroke patients. These instruments assess the degree of patient performance in activities and life situations, the required assistance, or the experienced difficulty. To our knowledge, no instrument really measures the satisfaction perceived by
stroke patients in their experience in activities and life situations, regardless of their degree of performance. Satisfaction corresponds to the person’s own perspective on his performance in activities and life situations that meets his need. With a patient-focused approach, it is important to measure satisfaction so that the rehabilitation process meets the needs that are essential to the patient’s well-being (Larsson et al. 2005).

Satisfaction is a latent variable concealed within person in the same manner as pain or anxiety. Satisfaction can be measured by eliciting the patient’s perceived satisfaction with life situations using a questionnaire with ordered categories. Such an instrument generates ordinal data that have no metric properties, since they rely on counts of potentially unequal units (Merbitz 1989; Wright 1997; Wright 1989). Consequently, they are not subject to statistics or mathematical operations such as addition or subtraction (Grimby et al. 1996). Linearity is not obtained when ordinal total scores are used. Linearity implies that the unit of measurement is consistent throughout the scale, so that identical intervals represent the same amount of the variable purported to be measured (Wright 1989). A linear measure of satisfaction can only be properly estimated from ordinal raw scores according to probabilistic measurement models, the most promising of these being the Rasch model (Rasch 1960). The aim of this was to develop a Rasch-built questionnaire which measures the satisfaction of adult chronic stroke patients.
1.2. Subjects and Methods

1.2.1. Subjects

This study was authorized by the ethics committee of the Université catholique de Louvain, Faculty of Medicine in Brussels, Belgium.

All patients in the present study were older than 18 years and presented with a unilateral hemiplegia subsequent to a stroke that had occurred at least six months earlier. Given that the data came from patients' perceptions, only patients showing no major cognitive deficits were selected (≥ 24 out of 30 on the Mini-Mental State Examination) (Folstein et al. 1975). As a result, 101 patients (30 females, 71 males; mean age: 63 years) met the inclusion criteria. According to the Hospital Anxiety Depression Scale (Zigmond et al. 1983), most of them were not depressed. They were asked to report their perceived satisfaction to one of four occupational therapists who each assessed approximately 25 patients. The four occupational therapists did not receive specific training. The sample description is presented in Table 1.
### Table 1. Sample description (n = 101)

<table>
<thead>
<tr>
<th>Description</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>71</td>
</tr>
<tr>
<td>Female</td>
<td>30</td>
</tr>
<tr>
<td>Age, y*</td>
<td>63 (25-90)</td>
</tr>
<tr>
<td>CVA side</td>
<td></td>
</tr>
<tr>
<td>Right brain</td>
<td>45</td>
</tr>
<tr>
<td>Left brain</td>
<td>56</td>
</tr>
<tr>
<td>Delay since stroke, mo*</td>
<td>52 (5-375)</td>
</tr>
<tr>
<td>Residence place</td>
<td></td>
</tr>
<tr>
<td>Home residence</td>
<td>62</td>
</tr>
<tr>
<td>Nursing home residence</td>
<td>39</td>
</tr>
<tr>
<td>Social status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>66</td>
</tr>
<tr>
<td>Unmarried</td>
<td>35</td>
</tr>
<tr>
<td>Depression status (%)</td>
<td></td>
</tr>
<tr>
<td>Non-depressed (HADS &lt; 11)</td>
<td>74</td>
</tr>
<tr>
<td>Depressed (HADS &gt;11)</td>
<td>26</td>
</tr>
</tbody>
</table>

*Mean (range)

### 1.2.2. Questionnaire Development

A large pool of items (271 items) was designed to cover at the wide range of stroke patients’ activities and life situations. They were selected from the nomenclature of the International Classification of Functioning, Disability and Heath (World Health Organization 2001) and from various existing scales (Fougeyrollas et al. 2001; Lepage et al. 1998; McHorney et al. 1994). This pool of items was evaluated by 10 stroke patients and 10 health professionals who work with chronic stroke patients. Patients and professionals were asked to appraise the clinical relevance of the activities and life situations.
Eighty-four items were considered clinically relevant by these experts and were included in the experimental version of the SATIS-Stroke questionnaire. The 84 items cover the nine domains of the ICF: learning and applying knowledge (4 items); general tasks and demands (3 items); communication (10 items); mobility (15 items); self-care (21 items); domestic life (6 items); interpersonal interactions and relationships (11 items); major life areas (4 items), and, community, social and civic life (5 items).

1.2.3. **Instrument**

The experimental version of SATIS-Stroke was given to 101 stroke patients. For each question, the patients were asked to define their perceived satisfaction with activities and participation on a four-level scale: Very Dissatisfied (0), Dissatisfied (1), Satisfied (2), or Very Satisfied (3). Activities and situations that were not encountered in the last month or were never performed were scored as "Not Applicable" and were encoded as missing responses. Missing values were observed in 30% of the responses (8484) given by all patients (n=101) to all items (n=84).

1.2.4. **Procedure**

The French version of the questionnaire was presented to chronic stroke patients in nursing homes or at home. The patients were asked to fill out the questionnaire without assistance, except for the first five items, which were completed with the assistance of the examiner. The items were presented in a random order to avoid any systematic effect.
The questionnaire was submitted twice to each subject after an interval of 32 days (SD 10). The first assessment was used to select the items and to calibrate the scale. The second assessment was used to verify the test-retest reliability of the final version of the SATIS-Stroke scale.

1.2.5. **Data Analysis**

Patients’ responses were analyzed with the RUMM 2020® Rasch analysis software. For all items, the response categories were analyzed according to the rating scale model (Andrich 1996b). The Rasch model is a probabilistic model based on the assumption that most satisfied persons have a higher probability of choosing a category reflecting higher satisfaction than less satisfied persons, and *vice versa*.

The model requires that the probability of choosing any response category to an item depends solely on the patient’s satisfaction and the satisfactory level in his activity and life situation (Prieto et al. 2003). In the case of satisfaction measurement, no attribute of the person or item besides satisfaction is theorized to account for the probability of choosing a response. This requirement, called “unidimensionality”, is essential for achieving an objective measurement (Andrich 1988; Wright 1989). Once the observed responses are found to fit the unidimensionality requirements, the Rasch model can be used to estimate the satisfaction of each subject and the satisfactory level of each item or threshold on a common linear interval scale (Merbitz 1989; Rasch 1960).
1.2.6.  **Item Selection**

Starting with 84 items, successive analyses were used to select items that constituted the final SATIS-Stroke scale. Individual items that did not meet any of the following criteria were eliminated. These criteria are presented in accord with the order of analysis.

1.2.6.1.  **Ordered Rating Scale**

The patients were asked to report their perception on a four-level scale: Very Dissatisfied (0), Dissatisfied (1), Satisfied (2), Very Satisfied (3). If the anticipated order of response categories is verified, subjects with a higher satisfaction should select a higher response to any given item, and subjects selecting a higher response for a given item should demonstrate higher satisfaction. When these conditions were not met, the order of thresholds between successive response categories was reversed, indicating that the rating scale was not used as anticipated for that particular item. Only items having thresholds in the anticipated order were retained.

1.2.6.1.1.  **Items with similar relative threshold locations**

Though all items were answered according to the same four-level rating, the threshold locations (relative to the item location) could vary across items (Linacre 2000a; Wright 1999). The difference in the relative threshold locations from one item to another complicates the clinical interpretation of scores since a given response has a different relative weight across all
items. Therefore, items with relative threshold locations significantly different from the average (Z-test) were removed.

1.2.6.1.2. **Items Fit a Unidimensional Scale**

Chi-squared fit statistics and Principal Component Analysis (PCA) on the residuals were used to detect items that did not satisfy the model requirement of unidimensionality. The total sample was divided into four class intervals (CI) of increasing satisfaction levels. An item chi-squared fit statistic was computed as the sum of the squared standardised residuals of each CI (i.e., the difference between the observed and expected responses) (Andrich D 1988). Items with a p-value lower than 0.05 indicate a threat to the fit requirement and were removed. However, some recent simulation studies have shown that good fit statistics may be reported when the scales are multidimensional. This is why a PCA on the residuals should be undertaken which gives the percentage of variance attributable to the Rasch factor and the first residual factor. According to Everett Smith’s general approach (Smith 2002b), independent t-tests can be used to compare the estimates for each subject which derive from the highest positive and negative loadings items (correlated at 0.3 and above with the component) on the first principal component of the residuals. The scale is considered as unidimensional when the percentage of tests outside the range ±1.96 is less than 5%.

After item selection, the SATIS-Stroke measures (expressed in logits and obtained at the first assessment) were used to test the invariance, validity, and reliability of the final version of the scale.
1.2.7. **Scale Invariance**

The invariance of the SATIS-Stroke scale was tested across different subgroups of chronic stroke patients. Provided that the data fit the requirement of the Rasch model, the score observed for an item should not be influenced by any factors other than the satisfaction level of the subjects. SATIS-Stroke scale should work similarly for males and females, younger and older patients, etc. If this is not the case, the item is biased or presents “differential functioning”. Different item functioning (DIF) was measured by computing a t-test for the difference between the difficulties of each item, estimated separately for two subgroups. This procedure is identical to the graphical method reported by Wright and Stone (Wright 1979) where the relative item difficulties of two subgroups are contrasted in an x-y plot using a 95% confidence interval. Six DIF subgroups of chronic stroke patients were formed based on the following criteria: 1. gender (males vs. females), 2. age (≥ 64 years vs. < 64 years old, split at the median age), 3. social status (married vs. unmarried), 4. place of residence (home residents vs. nursing home residents), 5. delay since stroke (≥ 37 months vs. < 37, split at the median delay), and 6. CVA side (left vs. right).

1.2.8. **Convergent Scale Validity**

The convergent validity was examined by using a Pearson’s correlation between SATIS-Stroke (a satisfaction measure) and the Barthel Index (a functional independence measure). Indeed, there is a high probability that patients who are more independent will report a greater satisfaction with
activities and participation as well as the converse (Hartman-Maeir et al. 2007).

1.2.9. Scale Reliability

Reliability of Internal Consistency. An estimate of the scale’s internal reliability is available as a Person Separation Index. It was computed as the ratio between the true measured standard deviation (as expressed by the observed standard deviation corrected for measurement error) and the error measure standard deviation. The Person Separation Index allows the calculation of the number of satisfaction levels that may be statistically distinguished in the sample (Fisher 1992).

Test-retest reliability. The test-retest reliability was investigated by comparing the subject’s responses and the satisfactory item hierarchy obtained at the first and the second assessment. To put the measures on the same scale, the adjustment of the origin of both calibrations was obtained by anchoring the items/thresholds of the second calibration at the satisfactory level of the first one. The test–retest reliability of the subject’s responses was determined by an Intraclass Correlation Coefficient (ICC). Moreover, the invariance of the satisfactory item hierarchy across the first and second assessments was also investigated through a DIF test (Wright 1979).

1.2.10. Relationship of SATIS-Stroke Measure to Demographic and Clinical Variables

The relationships between the SATIS-Stroke measures and different demographic (gender, age, social status, type of residence) and clinical
(delay since stroke, CVA side) indices were investigated. A Pearson’s correlation coefficient was computed for continuous indices and a t-test for nominal indices. A multi-way univariate ANOVA analysis was also performed to detect the effects of possible interactions between each of the variable.

1.2.11. Discarded Item Analysis

An analysis using items that did not fit the model was performed to verify that the discarded items did not represent a new scale.

1.3. RESULTS

From the 84-item set, 10 items showed a disordered rating scale, 4 items had relative threshold locations significantly different from the average, and 34 items did not fit a unidimensional scale, leaving a 36-item questionnaire. The results described hereafter refer to the 36-item questionnaire, except the discarded item analysis section.

1.3.1. Metric Properties

The subjects’ measures and the items’ threshold distributions are presented in Figure 1. The satisfaction scale is calibrated in logits (i.e., log-odds units), a probability unit that expresses the natural logarithm of the odds of being satisfied (i.e., the satisfied/unsatisfied probability ratio). At any given satisfaction level, a 1-logit difference between two patients indicates that their odds of being satisfied with performance in a given activity or life situation are 2.71:1 (i.e., $e^1$:1), a 2-logit difference indicates 7.4:1 odds (i.e.,
e^0:1), and so on. The average measure of our sample was 0.41 logits, which indicates that our chronic stroke patients are relatively satisfied with their level activities and participation. The items are well-targeted on the subjects’ measures. The distribution of the items shows few gaps, although the range of the scale is narrow (3.66 logits).

Figure 1: Satisfaction scale as perceived by adult chronic stroke patients. Top panel: distribution of subjects’ measures. Bottom panel: distribution of item thresholds (36 items, 108 thresholds).

The final questionnaire includes 36 items and covers the 9 ICF domains: learning and applying knowledge (1 item); general tasks and demands (1 item); communication (6 items); mobility (6 items); self-care (9 items); domestic life (3 items); interpersonal interactions and relationships (6 items); major life areas (1 item) and community, social and civic life (3 items).
The calibration of the 36-item SATIS-Stroke scale is presented in Table 2. The items are sorted, from top to bottom, in order of decreasing satisfactory level. “Moving outside your home in all circumstances” was the item requiring the highest satisfactory level to be performed, while “Listening to and looking at television according to my needs” was the item requiring the lowest satisfactory level. Table 2 reports the standard error (SE) associated with each item (mean: 0.13 logits; range: 0.13 to 0.16 logits); these values comply with the expectations for most variables (Linacre 1994). The chi-square (ChiSq) and its probability indicate that all 36 items are consistent with the definition of a unidimensional measure of the satisfaction with activities and participation (Mean ChiSq : 2.82; mean probability: 0.66) (Smith 2002b). The percentage of individual t-tests outside the range ± 1.96 (95% CI) was 4% which would be significant, indicating unidimensionality.

1.3.2. Description of SATIS-Stroke

The definition and use of the SATIS-Stroke scale are depicted in Figure 2. The top panel shows the distribution of satisfaction measures of chronic stroke patients. Patients reported satisfaction ranged from -1.51 to 4.00 logits.

The bottom panel illustrates the ogival relationship between the finite total raw scores (from 0 to 108) and the infinite satisfaction measures. This relationship is approximately linear between total raw scores of 20 and 90. In this central range, the change in satisfaction corresponding to a non-linear unitary increment in total score is equal to 0.07 logits. Outside of this central range, a unitary progression in the total score accounts for an increasing amount of satisfaction. For instance, an increase of 0.53 logits corresponds to a unitary increment in total score from 1 to 2: this sevenfold difference demonstrates the non-linearity of the total score.
The middle panel shows the expected response to a given item as a function of the underlying satisfaction measure. By comparing the satisfaction of a given stroke patient to the satisfactory level for each item, it is possible to determine the expected score of the patient for the item. For instance, a patient with a total score of 80 (1.06 logits) would be expected to respond “Satisfied” for the 17 first items and “Very Satisfied” for the other items. In contrast, a patient with a total score of 20 (-1.49 logits) has a high probability of responding “Very Dissatisfied” for the 27 first items and “Dissatisfied” for the other items. In our sample, 62% of the patients should be satisfied, or very satisfied with their performance in all activities and life situations listed: ten percent of patients should be very satisfied; one percent of patients should be very unsatisfied.
<table>
<thead>
<tr>
<th>Item</th>
<th>Location</th>
<th>Logits</th>
<th>SE</th>
<th>ChiSq</th>
<th>Probability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moving outside your home in any circumstances</td>
<td>.46</td>
<td>3.07</td>
<td>.13</td>
<td>0.44</td>
<td>.00</td>
</tr>
<tr>
<td>Getting clothes out of the closet</td>
<td>.34</td>
<td>2.79</td>
<td>.12</td>
<td>3.63</td>
<td>.06</td>
</tr>
<tr>
<td>Eating and drinking in all circumstances and according to your needs</td>
<td>.14</td>
<td>1.06</td>
<td>.07</td>
<td>0.01</td>
<td>.38</td>
</tr>
<tr>
<td>Reaching objects in your closest space</td>
<td>.16</td>
<td>1.22</td>
<td>.07</td>
<td>1.43</td>
<td>.23</td>
</tr>
<tr>
<td>Participating in arts and culture</td>
<td>.17</td>
<td>0.85</td>
<td>.05</td>
<td>0.23</td>
<td>.49</td>
</tr>
<tr>
<td>Preparing and eating your home according to your needs</td>
<td>.17</td>
<td>0.80</td>
<td>.05</td>
<td>0.00</td>
<td>.30</td>
</tr>
<tr>
<td>Taking your bath or your shower according to your needs</td>
<td>.18</td>
<td>0.57</td>
<td>.04</td>
<td>0.00</td>
<td>.39</td>
</tr>
<tr>
<td>Washing your hair according to your needs</td>
<td>.32</td>
<td>0.63</td>
<td>.04</td>
<td>0.00</td>
<td>.29</td>
</tr>
<tr>
<td>Participating in spoken exchanges of information with your entourage</td>
<td>.31</td>
<td>0.62</td>
<td>.04</td>
<td>0.00</td>
<td>.30</td>
</tr>
<tr>
<td>Managing your incomes in all circumstances</td>
<td>.31</td>
<td>0.58</td>
<td>.04</td>
<td>0.00</td>
<td>.30</td>
</tr>
<tr>
<td>Using coins and banknotes in all circumstances</td>
<td>.31</td>
<td>0.56</td>
<td>.04</td>
<td>0.00</td>
<td>.30</td>
</tr>
<tr>
<td>Getting a sexual relationship with someone</td>
<td>.52</td>
<td>1.06</td>
<td>.07</td>
<td>1.43</td>
<td>.23</td>
</tr>
<tr>
<td>Participating in occupational activities</td>
<td>.41</td>
<td>0.74</td>
<td>.05</td>
<td>0.00</td>
<td>.10</td>
</tr>
<tr>
<td>Climbing and going downstairs in your home according to your needs</td>
<td>.47</td>
<td>0.88</td>
<td>.05</td>
<td>0.00</td>
<td>.10</td>
</tr>
<tr>
<td>Moving outside your home in any circumstances</td>
<td>.41</td>
<td>0.82</td>
<td>.05</td>
<td>0.00</td>
<td>.10</td>
</tr>
<tr>
<td>Items</td>
<td>Location</td>
<td>Logits</td>
<td>SE</td>
<td>ChiSq</td>
<td>Probability</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>-----------</td>
<td>--------</td>
<td>-----</td>
<td>-------</td>
<td>-------------</td>
</tr>
<tr>
<td>Ensuring that your rights are respected</td>
<td>0.02</td>
<td>0.13</td>
<td>2.81</td>
<td>0.59</td>
<td></td>
</tr>
<tr>
<td>Making your personal hygiene according to your needs</td>
<td>-0.01</td>
<td>0.13</td>
<td>5.81</td>
<td>0.21</td>
<td></td>
</tr>
<tr>
<td>Asking for help in an emergency situation</td>
<td>-0.07</td>
<td>0.13</td>
<td>4.12</td>
<td>0.39</td>
<td></td>
</tr>
<tr>
<td>Reading and understanding a document in all circumstances</td>
<td>-0.08</td>
<td>0.13</td>
<td>7.70</td>
<td>0.10</td>
<td></td>
</tr>
<tr>
<td>Moving inside your home</td>
<td>-0.08</td>
<td>0.13</td>
<td>3.83</td>
<td>0.43</td>
<td></td>
</tr>
<tr>
<td>Choosing appropriate clothes</td>
<td>-0.30</td>
<td>0.14</td>
<td>1.21</td>
<td>0.67</td>
<td></td>
</tr>
<tr>
<td>Participating in ceremonies (marriage, gathering family, etc.)</td>
<td>-0.31</td>
<td>0.13</td>
<td>7.77</td>
<td>0.10</td>
<td></td>
</tr>
<tr>
<td>Maintaining emotional relationships</td>
<td>-0.33</td>
<td>0.13</td>
<td>1.16</td>
<td>0.88</td>
<td></td>
</tr>
<tr>
<td>Expressing oneself to someone</td>
<td>-0.34</td>
<td>0.13</td>
<td>4.07</td>
<td>0.39</td>
<td></td>
</tr>
<tr>
<td>Participating in food and drink preparation in all circumstances</td>
<td>-0.35</td>
<td>0.13</td>
<td>3.38</td>
<td>0.43</td>
<td></td>
</tr>
<tr>
<td>Having an urinary continence in your home and outside of this one</td>
<td>-0.36</td>
<td>0.13</td>
<td>2.77</td>
<td>0.64</td>
<td></td>
</tr>
<tr>
<td>Choosing appropriate clothes</td>
<td>-0.37</td>
<td>0.13</td>
<td>1.21</td>
<td>0.67</td>
<td></td>
</tr>
<tr>
<td>Participating in ceremonies (marriage, gathering family, etc.)</td>
<td>-0.38</td>
<td>0.13</td>
<td>4.07</td>
<td>0.39</td>
<td></td>
</tr>
<tr>
<td>Maintaining emotional relationships</td>
<td>-0.39</td>
<td>0.13</td>
<td>3.38</td>
<td>0.43</td>
<td></td>
</tr>
<tr>
<td>Listening to and watching al television according to your needs</td>
<td>-0.40</td>
<td>0.13</td>
<td>2.77</td>
<td>0.64</td>
<td></td>
</tr>
<tr>
<td>Moving inside your home</td>
<td>-0.41</td>
<td>0.13</td>
<td>1.21</td>
<td>0.67</td>
<td></td>
</tr>
<tr>
<td>Asking for help in an emergency situation</td>
<td>-0.42</td>
<td>0.13</td>
<td>4.07</td>
<td>0.39</td>
<td></td>
</tr>
<tr>
<td>Making your personal hygiene according to your needs</td>
<td>-0.43</td>
<td>0.13</td>
<td>3.38</td>
<td>0.43</td>
<td></td>
</tr>
<tr>
<td>Ensuring that your rights are respected</td>
<td>-0.44</td>
<td>0.14</td>
<td>6.32</td>
<td>0.18</td>
<td></td>
</tr>
<tr>
<td>Co-operating with your entourage</td>
<td>-0.45</td>
<td>0.13</td>
<td>5.34</td>
<td>0.25</td>
<td></td>
</tr>
<tr>
<td>Opening and closing doors in your home</td>
<td>-0.46</td>
<td>0.13</td>
<td>4.10</td>
<td>0.39</td>
<td></td>
</tr>
<tr>
<td>Co-operating with your entourage</td>
<td>-0.47</td>
<td>0.13</td>
<td>3.13</td>
<td>0.54</td>
<td></td>
</tr>
<tr>
<td>Participating in ceremonies (marriage, gathering family, etc.)</td>
<td>-0.48</td>
<td>0.13</td>
<td>2.41</td>
<td>0.67</td>
<td></td>
</tr>
<tr>
<td>Participating in ceremonies (marriage, gathering family, etc.)</td>
<td>-0.49</td>
<td>0.13</td>
<td>1.61</td>
<td>0.88</td>
<td></td>
</tr>
<tr>
<td>Expressing oneself to someone</td>
<td>-0.50</td>
<td>0.13</td>
<td>3.00</td>
<td>0.40</td>
<td></td>
</tr>
<tr>
<td>Participating in ceremonies (marriage, gathering family, etc.)</td>
<td>-0.51</td>
<td>0.13</td>
<td>2.13</td>
<td>0.64</td>
<td></td>
</tr>
<tr>
<td>Choosing appropriate clothes</td>
<td>-0.52</td>
<td>0.13</td>
<td>1.21</td>
<td>0.67</td>
<td></td>
</tr>
<tr>
<td>Participating in ceremonies (marriage, gathering family, etc.)</td>
<td>-0.53</td>
<td>0.13</td>
<td>4.07</td>
<td>0.39</td>
<td></td>
</tr>
<tr>
<td>Maintaining emotional relationships</td>
<td>-0.54</td>
<td>0.13</td>
<td>3.38</td>
<td>0.43</td>
<td></td>
</tr>
<tr>
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<td>-0.55</td>
<td>0.13</td>
<td>2.77</td>
<td>0.64</td>
<td></td>
</tr>
<tr>
<td>Moving inside your home</td>
<td>-0.56</td>
<td>0.13</td>
<td>1.21</td>
<td>0.67</td>
<td></td>
</tr>
<tr>
<td>Asking for help in an emergency situation</td>
<td>-0.57</td>
<td>0.13</td>
<td>4.07</td>
<td>0.39</td>
<td></td>
</tr>
<tr>
<td>Making your personal hygiene according to your needs</td>
<td>-0.58</td>
<td>0.13</td>
<td>3.38</td>
<td>0.43</td>
<td></td>
</tr>
<tr>
<td>Ensuring that your rights are respected</td>
<td>-0.59</td>
<td>0.13</td>
<td>2.81</td>
<td>0.64</td>
<td></td>
</tr>
</tbody>
</table>

**Summary Statistics:**
- Person Location: 0.498
- Item-Trait Interaction: 0.66
- Reliability Indices: 0.94
Figure 2: Top panel: distribution of satisfaction measures of chronic stroke patients. Middle panel: a patient’s expected score to each item as a function of the underlying satisfaction measure. A satisfaction measure of zero is by convention set as the average item satisfaction level. Bottom panel: ogival relationship between total score (from 0 to 108 points) and satisfaction measure.
1.3.3. Scale Invariance

The invariance of the SATIS-Stroke scale was validated across six demographic and clinical subgroups of chronic stroke patients (Andrich 2004). Figure 3 illustrates the satisfactory level hierarchy of SATIS-Stroke items across the different demographic and clinical patient subgroups. Most of the items were within the 95% confidence interval of the identity line, indicating that the SATIS-Stroke scale can be used to measure satisfaction in chronic stroke patients regardless of their gender, age, social status, place of residence, delay since stroke, and CVA side. There are minor exceptions; for instance “Expressing oneself to someone according to your needs” (Item 27) was estimated to require a higher satisfaction level for females than for males, “Using storage spaces in your home” (Item 17) appeared to require a lower satisfaction level for home residents than for nursing home residents.
1.3.4. **Scale Validity**

SATIS-Stroke measures were significantly related to the Barthel Index raw scores ($R=0.74$, $p<0.05$), confirming that being independent in activities and life situations has an important effect on the satisfaction perceived by the patients.
1.3.5. **Scale Reliability**

A person separation reliability of 0.94 was found for SATIS-Stroke, indicating that the scale allows six satisfaction levels to be statistically distinguished in our sample.

The test-retest reliability (interval: 32 days – SD 10) of the subject measures is presented in Figure 4. Patients' perceived measures at the first and second assessments were highly correlated (ICC = 0.98, p<0.001). Most of the measures (98%) lie within the 95% confidence interval of the identity line, indicating that adult stroke patients tend to estimate their satisfaction over time in a consistent manner. Moreover, the satisfactory level hierarchy of all 36 SATIS-Stroke items was maintained between the first and second assessments, indicating that the scale is invariant across time.
Figure 4: Left panel: Relationship between the satisfaction measures as perceived by the stroke patients at the first and the second assessments (interval: 32 days; SD 10) and 95% confidence interval (solid lines) of the ideal invariance. More satisfied persons are plotted in the top right part of the panel. Patients’ measures (dots) lying within the control lines have the same estimated satisfaction at the first and the second assessment. Right panel: Differential Item Functioning plot of the item satisfactory level perceived by the stroke patients across time and 95% confidence interval (solid lines) of the ideal invariance. Items requiring the highest satisfaction levels to be performed are plotted in the top right part of the panel. All items (dots) lie within the control lines indicating that they have the same estimated satisfactory levels at the first and second assessments.

1.3.6. Relationship of SATIS-Stroke Measure to Demographic and Clinical Variables

The effects of demographic and clinical variables on SATIS-Stroke measures are presented in Table 3. No significant difference in satisfaction measures was observed across gender, social status, and clinical variables (i.e., delay after stroke and CVA side). The place of residence and age were
significantly related to SATIS-Stroke measures. Home residents demonstrated a higher satisfaction overall than nursing home residents; additionally, younger chronic stroke patients were generally more satisfied than older ones. No interaction effects were observed between any of the demographic and clinical variables.

Table 3: Relationship of SATIS-Stroke measures to demographic and clinical variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Statistic*</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>ρ = 0.016</td>
<td>0.874</td>
</tr>
<tr>
<td>Age</td>
<td>ρ = -0.272</td>
<td>0.006</td>
</tr>
<tr>
<td>Social status</td>
<td>ρ = 0.190</td>
<td>0.057</td>
</tr>
<tr>
<td>Residence place</td>
<td>ρ = -0.289</td>
<td>0.003</td>
</tr>
<tr>
<td>Delay since stroke</td>
<td>ρ = 0.033</td>
<td>0.744</td>
</tr>
<tr>
<td>CVA side</td>
<td>ρ = 0.149</td>
<td>0.137</td>
</tr>
</tbody>
</table>

*Reported statistics are as follows: ρ for Rho de Spearman.

1.3.7. Discarded items analysis

Two post-hoc analyses were performed respectively on the 48 removed items and the 34 misfitting items to verify the potential for a second subscale. Neither the 48 removed items nor the 34 misfitting items formed a second valid, reliable (R=0.53; 0.63), and unidimensional scale (Mean ChiSq: 3.92; 2.85 – mean probability: 0.03; 0.07).
1.4. Discussion

The purpose of this study was to validate a satisfaction measure of activities and participation in the actual environment experienced by chronic stroke patient using the Rasch measurement model. This measure was calibrated in a sample of 101 stroke patients. From the original pool of 84 items, 36 items were retained for the final SATIS-Stroke questionnaire. The items shared the same ordered rating scale structure, had relative threshold locations similar to the average, and defined a unidimensional and linear scale.

The Rasch model was used to construct the SATIS-Stroke scale. This model facilitated the calibration of SATIS-Stroke activities and life situations so that they could be sorted according to their estimated satisfactory level (figure 2) giving clinicians a tool to relate the total score of each patient to the satisfactory level of each item. Thus, clinicians can use a patient’s total score to rapidly generate a prediction of the activities and life situations that are satisfactory or dissatisfactory to the patient. This tool can help clinicians establish goal and to track (on a linear scale) the satisfaction level of each patient throughout the rehabilitation process. Furthermore, the Rasch model has the ability to detect discrepancies between the observed score for each item and the expected score, given the overall satisfaction measure of the subject. More than simply data quality control, the model can be used to identify idiosyncratic use of the questionnaire.

The Person Separation Reliability of SATIS-Stroke was 0.94, thus showing good precision across the sample. However, the range of the
SATIS-Stroke scale was narrow. The precision of a scale is not only determined by the number of items selected in the questionnaire (i.e., the range of the measurement scale) but also by the targeting between the items and the subjects' measures. In our sample, the 36 SATIS-Stroke items covered the whole range of satisfaction. Missing values may affect the accuracy of the estimates obtained by the Rasch model. In the final SATIS-Stroke scale, only 3% of the values were missing from the responses (n=3636) given by all patients (n=101) to all items (n=36). Moreover, the Rasch model is robust for analysing missing values (Andrich et al. 2003; Luo et al. 2005), and the proportion of missing values per item is reflected in the item standard error. In the present study, the standard errors associated with the item satisfactory level (mean: 0.41 logits) complied with the expectation for most variables (Linacre 1994).

The observed invariance in the item hierarchy after a delay of approximately 1 month indicated that the SATIS-Stroke measures were reproducible over time. The invariance of the SATIS-Stroke scale was verified across various demographic and clinical subgroups of chronic stroke patients. The SATIS-Stroke scale can therefore be used to measure satisfaction in chronic stroke patients regardless of their gender, age, social status, place of residence, delay since stroke, and CVA side. Some items presented a minor different item functioning (DIF) that did not compromise the clinical application of the questionnaire. All these metric properties give the scale reasonable potential to measure change in satisfaction with activities and life situations.
All aspects of patients’ performance in activities and life situations are represented, according to the ICF Core Set for Stroke (Geyh et al. 2004). The areas covered represent key issues for patients with stroke, including mobility, self-care, communication, and interpersonal interactions. The content of the hierarchical scale indicates that the more satisfactory items are predominantly related to communication (4 items) and interpersonal relationships (4 items) while less satisfactory items are predominantly related to mobility (5 items) and self-care (5 items). This suggests that physical limitations and functional dependence may decrease the satisfaction and probably the well-being experienced by the patients in their activities and life situations. This is consistent with the good relationship observed between the Barthel Index and SATIS-Stroke (R=0.74) indicating that the lower the functional independence, the lower the patient satisfaction and inversely.

The average satisfaction of our sample of patients was slightly above the average satisfaction level for the questionnaire. This could be explained by the relatively long delay after stroke (mean: 58 months), which gave patients time to readjust their goals and values in order to find a new way of living as they desired (Cardol et al. 2002a). The relatively good mean satisfaction level observed could also arise from the youthfulness of our sample (mean age: 63 years old), and its low depressive symptoms (Mean of Hospital Anxiety Depression Scale (Zigmond & Snaith 1983) score: 6.69).

In our sample, a significant relationship was found between SATIS-Stroke and age confirming previous studies showing a significant link
between age and the occurrence of a handicap situations (Desrosiers et al. 2006; Desrosiers et al. 2002). Younger chronic stroke patients were more satisfied than older ones; this may be due to the ability of younger stroke patients to adapt themselves more easily to new life habits imposed by stroke than older ones. Satisfaction level was also significantly lower among nursing home residents to home residents; one possible explanation for this is that in nursing homes residents may be feel inclined to resign themselves to a more dependent life, such that their level of satisfaction depends on how nursing assistants meet their needs. In contrast, residents living at home tend to perform more actively activities and life situations with the assistance of their family; this could lead to a better perception of satisfaction by the patient.

The SATIS-Stroke scale was developed to measure the satisfaction of patients who have suffered a chronic stroke, the most frequent neurological diagnosis of adults who are receiving physical therapy. The scale focuses on the satisfaction of chronic stroke patients with their performance in activities and life situations. The exclusion of patients with cognitive deficits and the young average age of our sample may not be representative of all chronic stroke patients.

The metric properties of SATIS-Stroke constitute an encouraging starting point for further investigation. A sample size of 100 patients is an adequate population for the calibration of a well-constructed instrument if it is well-targeted (Linacre 1994; Wright 1996). Nevertheless, one must be wise when the sample is split into subgroups such as in the DIF (Tristan 2006).
The questionnaire is easy to administer and require little time to complete (15 minutes). SATIS-Stroke appears, at least in our sample, to be precise enough to discriminate patients’ satisfaction levels and, presumably, to capture even subtle satisfaction changes over time. However, future research is required to empirically verify the responsiveness of SATIS-Stroke for evaluating acute and chronic stroke patients. Moreover, we hope that the SATIS-Stroke scale will eventually be applied to evaluate other diseases in adults with the prospect of building a generic measure of adult patient satisfaction with activities and participation.
Chapter 2

Changes in satisfaction with activities and participation between acute, post-acute and chronic stroke phases: A responsiveness study of the SATIS-Stroke questionnaire

Abstract

Objective: To investigate clinical changes among the acute, post-acute and chronic phases in stroke patients’ satisfaction with activities and participation. The SATIS-Stroke questionnaire’s sensitivity to change was investigated with a sample of 45 stroke patients. Methods: The SATIS-Stroke questionnaire was used to collect data from the 45 patients (mean age 69 years, 64% men) in the acute, post-acute and chronic stroke phases. Responsiveness of the questionnaire was investigated using a sample approach (effect size and standardized response mean indices) and an individual approach ($t$ statistic). The clinical significance of change was also calculated using the empirical rule of effect size and the minimal clinically important difference. Results: Analysis of variance showed a significant difference among evaluations in the three phases ($F = 13.662; 2 \text{ df}; p < 0.001$). The post-hoc analysis showed a significant change between the acute and post-acute phases, but no significant change between the post-acute and chronic phases. Effect size and standardized response mean
indices showed that the greatest change in satisfaction with activity and participation was between the acute and the chronic phases. Analysis of the clinical significance of change indicated that greater changes in satisfaction were necessary to detect clinically relevant improvement over time than clinically relevant deterioration. *Conclusions:* The SATIS-Stroke questionnaire successfully determined changes in satisfaction among stroke patients.

2.1. **Introduction**

The International Classification of Functioning, Disability, and Health (ICF) (World Health Organization 2001) is a conceptual framework that provides health professionals with a common language for the description of human functioning (Jette et al. 2007). One fundamental goal of rehabilitation is to improve the patient’s abilities to manage daily activities and achieve autonomous living (Cardol et al. 2002a). The ICF defines three domains of functioning according to body, individual and social perspectives: body functions and structures, activity and participation. The present paper focuses on the ICF dimensions of activity and participation. An activity is defined as the execution of a task or action by an individual, and participation is defined as involvement in a life situation (World Health Organization 2001). Activity limitations are difficulties an individual may have in executing tasks, such as taking care of one’s physical appearance. Participation restrictions are problems an individual may experience with involvement in life situations, such as employment, education, spirituality and culture (Bickenbach et al. 1999).

Activity and participation can be measured in various ways: degree of patient performance in activities and life situations, required assistance, or experienced difficulty. These dimensions may also be measured as the satisfaction perceived by patients in their experience of activities and life situations, regardless of their degree of performance (Bouffioulx et al. 2008). Satisfaction with activity and participation is a latent variable corresponding to an individual’s perspective of whether his or her performance in activities...
and life situations meets his or her needs (Bouffioulx et al. 2008). The patient’s perceived satisfaction with activities and life situations may be measured with a questionnaire (Larsson et al. 2005).

The SATIS-Stroke questionnaire was developed to measure chronic stroke patients’ satisfaction with activity and participation in the actual environment (Bouffioulx et al. 2008). The validity, reproducibility, linearity and unidimensionality of this questionnaire have been demonstrated, but its responsiveness has not yet been tested. Responsiveness is the ability of a scale to clinically detect relevant changes over time (De Bruin et al. 1997; Finch et al. 2002; Wright et al. 1997). It is usually quantified by indices such as effect size (Kazis et al. 1989; Middel & van Sonderen 2002) and standardized response mean (Middel & van Sonderen 2002). The present study thus investigates the responsiveness of the SATIS-Stroke questionnaire by examining changes in satisfaction with activity and participation perceived by an adult stroke cohort during the acute, post-acute and chronic phases.

2.2. M A T E R I A L S  A N D  M E T H O D S

2.2.1. Subjects

This study was approved by the Medical Ethics Committees of the Université catholique de Louvain. Patients gave written informed consent before evaluation. The participants in this study were recruited from a sample of adult patients admitted to Belgian stroke units between March 2007 and
September 2008 with a primary diagnosis of stroke (CVA). Eligible stroke patients were identified by a review of weekly admission records.

To be included in this study, subjects must have suffered a confirmed eligible stroke as defined by the World Health Organization (WHO). The WHO defines stroke as “rapid onset of vascular origin reflecting a focal disturbance of cerebral function, excluding isolated impairments of higher function and persisting longer than 24 hours” (World Health Organization 1983). Subjects were excluded if they: (a) had stroke onset more than 8 days prior to admission; (b) were unable to care for themselves prior to stroke; (c) had stroke due to sub-arachnoid hemorrhage; (d) were not expected to survive for at least 6 months; or (e) were lethargic, obtunded, or comatose.

Forty-five patients (16 women, 29 men) with a mean age of 69 ± 10.7 years participated in the study. Demographics and baseline stroke characteristics are described in Table 1. The patients presented moderately impaired functional statuses as measured by the Stroke Impairment Assessment Set (SIAS) (Chino N et al. 1995), showed no major cognitive dysfunctions as observed with the Mini Mental State Examination (MMSE) (Folstein et al. 1975), and were not depressed as measured by the Hospital Anxiety Depression Scale (HADS) (Zigmond & Snaith 1983).
2.2.2. Procedure

The patients were followed up for six months after stroke onset. This period encompassed three clinical phases: (i) acute phase (one week after CVA onset); (ii) post-acute (recovery) phase (three months after CVA onset); and (iii) chronic phase (six months after CVA onset) (Mayo et al.)

Table 1: Sample description (n = 45)

<table>
<thead>
<tr>
<th>Characteristics</th>
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<tr>
<td>Sex n</td>
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<td>Impairment Status in</td>
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<td>SIAS, median (InterQuartile range)</td>
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<tr>
<td>Cognitive Status in</td>
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<td>MMSE, median (InterQuartile range)</td>
<td>21 (18-24)</td>
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<tr>
<td>Mood Status in</td>
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<tr>
<td>HADS, median (InterQuartile range)</td>
<td>6 (5-8)</td>
</tr>
</tbody>
</table>

CVA: Cerebrovascular Accident
SIAS: Stroke Impairment Assessment Set
MMSE: Mini Mental State Examination
HADS: Hospital Anxiety Depression Scale
Patients’ satisfaction with activity and participation was assessed three times (at intervals of 90 ± 15 days), during acute (one week: t1), post-acute (three months: t2) and chronic (six months: t3) phases. The patients were asked to characterize perceived changes in global functional status twice, during post-acute and chronic phases.

**Instrument**

Perceived satisfaction was measured using the SATIS-Stroke questionnaire. This questionnaire consists of items referring to 36 daily activities and life situations (Bouffioulx et al. 2008), with responses given on a four-level scale: (0) very dissatisfied, (1) dissatisfied, (2) satisfied and (3) very satisfied. It was developed using the Rasch model, which allows the conversion of ordinal scores into linear measures on a unidimensional scale (Rasch 1960). These linear measures are constantly expressed in logits (i.e., log-odd units a measurement unit constant throughout the measurement scale). When analyzing SATIS-Stroke questionnaire response data, a higher value in logits corresponds to a higher degree of satisfaction with activities and participation. The pre-established logits for transformation of our data according to Bouffioulx et al (Bouffioulx et al. 2008) were used.

The SATIS-Stroke questionnaire was used for three assessments (t1 - t3) to characterize patients’ perceived satisfaction in performing each activity and life situation, even if they used technical or human aids. The patients subjectively rated their perceptions of changes in global functional status between acute and post-acute phases, and between post-acute and chronic phases. These changes were expressed with an ordinal scale (0 - 10).
score of 5 indicated stable status, a score < 5 indicated deteriorating status and a score > 5 indicated an improved status.

2.2.3. Data analysis

2.2.3.1. Statistical method

Two approaches were used to verify the patient’s evolution between the different periods from one week to six months: a sample-approach and an individual-approach.

a. Sample-approach

There is no agreement regarding how best to test the sensitivity to change of measures. Therefore, repeated ANOVA, effect size and standardized response mean were calculated between each period (Middel & van Sonderen 2002).

a.1. The Repeated-measure ANOVA

The satisfaction changes between the periods were tested with a Repeated-Measure ANOVA. Subsequently, significant effects detected by the RM-ANOVA were investigated by a Tukey post-hoc analysis (Acute vs. Post-acute phases; Post-acute vs. Chronic phases and Acute vs. Chronic phases).

a.2. Effect size and Standardized Response Mean

Effect size (ES) enables the comparison of responsiveness between different studies or outcome measures by standardizing the change effect in units of standard deviation without influence from the sample size (Middel & van Sonderen 2002). Effect size is calculated as the mean change observed
between the average measures of two evaluations dividing by the standard deviation of the first evaluation measures. Consequently, effect size is sensitive to the distribution of the measures obtained during the first evaluation.

\[
ES = \frac{Mean \ Change}{SD_{t1}}
\]

Standardized response mean (SRM), index without unit, standardizes the change independent of sample size but incorporated information about change distribution (Liang MH et al. 1990). The SRM is calculated by dividing the mean measures’ change observed between two evaluations by the standard deviation of the measures change. Higher effect sizes and standardized response means correspond to a higher magnitude of changes between two evaluations.

\[
SRM = \frac{Mean \ Change}{SD_{change}}
\]

**b. Individual-approach**

The individual approach consists of taking into account the standard error of measurement associated with patient’s satisfaction measure displayed by the software. A statistic for each patient could be computed to test the extent to which the satisfaction measures had changed (Wright BD et al. 1979):

\[
t_{m12} = \frac{m_2 - m_1}{\sqrt{(SE_1)^2 + (SE_2)^2}}
\]
Where $m_1$ and $m_2$ are the satisfaction measures at the first and the second evaluation, respectively, and $SE_1$ and $SE_2$ are their associated standard errors of measurement. Moreover, the distribution of this $t$ statistic is approximately a standardized normal distribution (Wright BD & Stone MH. 1979). Therefore, patients with a $t$ statistic above 1.96 or below -1.96 will show a significantly improved or deteriorated satisfaction measure, respectively.

c. Clinical significance of change

Responsiveness implies the ability to detect a clinical important changes (Guyatt et al. 1987). To assess this clinical significance of change, Sloan et al. (Sloan J.A et al. 2003) summed up two principal methods. The first one, the empirical rule of effect size method (ERES) is a theoretical method, based upon the fact that 99% of any normal distribution falls into three standard deviations (SD) of the mean and that the measurement range of any instrument can be represented by six SD. If the measurement range is theoretically transformed into a range of 0 to 100, one SD would therefore correspond to 17 % (i.e. 100/6) of the measurement range (Sloan J.A et al. 2003). The ERES method, then, defines the clinical significance of change as one half SD according to Cohen’s classification system of effect size (0.2 times the SD = small change, 0.5 times the SD = moderate change, and 0.8 times the SD = large change) (Sloan J.A et al. 2003). The second method estimates a minimal clinically important difference (MCID) using, among others, a patient self-report global rating of change. In this study, to measure
a change in the patient’s health status, a patient’s self-report related to the perceived global functional status evolution was asked. This estimation of MCID was based upon the definition of Juniper et al. (Juniper et al. 1994), which define the MCID as “the smallest difference in score which patients perceived as beneficial...” In other words, the smallest change in the measure that patients perceive as meaningful and which would cause clinicians to consider a change in the patient’s management (Dawson J et al. 2007). The mean change in patients who reported an deteriorated or improved “small change” can therefore be considered as the MCID (Sloan J.A et al. 2003).

2.3. RESULTS

2.3.1. Statistical method

a. Sample-approach

a.1. The Repeated-Measure ANOVA

The mean satisfaction measures of the 45 patients were -1.19 logits SD = 1.43 logits in the acute phase, -0.09 logits SD = 1.22 logits in the post-acute phase and 0.42 logits SD = 1.80 logits in the chronic phase. The Analysis of Variance showed that the difference between the three evaluations is significantly different (F= 13.662; 2 df; p<0.001). The post-hoc analysis, illustrated in the figure 1, indicated that the mean satisfaction measure of patients with stroke significantly increased between the acute and post-acute phases (q=4.934; p<0.001) and between the acute and the chronic phases.
No significant difference was observed between the post-acute and chronic phases ($q=2.301$; $p>0.05$). The mean satisfaction measure observed at six months was similar to the one reported in the initial calibration of SATIS-Stroke questionnaire, strengthening its validity (Bouffioulx et al. 2008).

![Figure 1](image_url)

**Figure 1**: Mean (± SD) satisfaction (in logits) among chronic stroke patients in the acute (one week), post-acute (3 months) and chronic (6 months) phases. Significant differences between the three assessment periods are indicated by asterisks. The dotted black line represents the mean satisfaction with activity and participation found in the initial scale (0.41 logits).

### a.2. Effect size and Standardized Response Mean

The table 2 reports the responsiveness indices of the SATIS-Stroke questionnaire. The highest change in satisfaction measures with activity and participation was logically observed between the acute and the chronic...
phases as indicated by the ES and SRM. Higher change was observed between the acute and post-acute phases.

<table>
<thead>
<tr>
<th>Table 2: SATIS-Stroke responsiveness indices based on sample-approach</th>
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<tbody>
<tr>
<td>Phases</td>
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<tr>
<td>---------------------------------------</td>
</tr>
<tr>
<td>Post-acute vs. Acute</td>
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<tr>
<td>SATIS-Stroke</td>
</tr>
<tr>
<td>Chronic vs. post-acute</td>
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<tr>
<td>Chronic vs. Acute</td>
</tr>
</tbody>
</table>

SRM = Standardized Response Mean

**b. Individual-approach**

Figure 2 shows the changes in satisfaction computed with the t statistic. Between the acute and post-acute phases, 29 patients (64%) who expressed a significant improvement ($t > 1.96$) presented a mean change in satisfaction of 2.09 logits, while 6 patients (14%) who expressed a significant deterioration ($t < -1.96$) presented a mean satisfaction change of -2.30 logits. Eight patients (18%) who reported a non-significant improvement ($0 < t < 1.96$) presented a mean change in satisfaction of 0.39 logits during the same period.
Figure 2: Number (left ordinate) and percentage (right ordinate) of patients according to satisfaction changes expressed as a $t$ statistic: $t > 1.96 =$ significantly improved; $1.96 > t > 0 =$ improved; $t = 0 =$ no change; $0 > t > -1.96 =$ deteriorated; $t < -1.96 =$ significantly deteriorated. Data are reported as comparisons of the three assessments (black bar: post-acute vs. acute; light gray bar: chronic vs. post-acute; medium gray bar: chronic vs. acute).

Between the post-acute and chronic phases, 17 patients (38%) who expressed a significant improvement presented a mean satisfaction change of 2.36 logits, while 9 patients (20%) who expressed a significant deterioration presented a mean satisfaction change of -2.03 logits. Nine patients (20%) who expressed a non-significant improvement presented a mean change in satisfaction of 0.56 logits, while 9 patients (20%) who
expressed a non-significant deterioration presented a mean change of -0.43 logits during the same period.

c. Clinical significance of change

As the range of the initial SATIS-Stroke questionnaire was equal to 10.19 logits, one theoretical SD corresponds to 1.70 logits (10.19 logits/6). Consequently, ERES defines clinically significant change as equivalent to 0.34 logits (0.2 times the SD) for a small change, 0.85 logits (0.5 times the SD) for a moderate change and 1.36 logits (0.8 times the SD) for a large change.

The MCID of all patients between the acute and post-acute phases indicated that 14 patients who reported a deteriorated status (perceived change in global functional status < 5) presented a mean decrease in satisfaction of 0.23 ± 2.31 logits, while 23 patients who reported an improved status (perceived change in global functional status > 5) presented a mean increase in satisfaction of 1.77 ± 1.27 logits. In contrast, the MCID of all patients between the post-acute and chronic phases showed that 12 patients who reported a deteriorated status presented a mean decrease in satisfaction of -0.97 logits (SD = 1.28 logits), while 19 patients who reported an improved status showed a mean increase in satisfaction of 1.45 logits (SD = 1.24 logits).
2.4. Discussion

The present study investigated the responsiveness of the SATIS-Stroke questionnaire by examining the changes in satisfaction with activity and participation perceived by 45 adult stroke patients among the acute, post-acute and chronic phases. A patient-focused approach showed that satisfaction significantly increased between the acute and the post-acute phases. However, no significant satisfaction change was observed between the post-acute and chronic phases. These results are confirmed by the ES and SRM indices. During the acute phase, the patients were critically ill and therefore frequently bedridden with short standing and ambulatory periods. Moreover, they required substantial assistance in meeting basic needs. Physical, occupational and speech therapy became progressively important and served patients’ needs to recover the loss of functions (Kirkevold 2002). At the beginning of the post-acute phase, patients’ returns to a home environment may have contributed to greater optimism, expressed in their perceived satisfaction with activities and participation (Ljunberg et al. 2001). In the post-acute phase, patients gradually regained psychological well-being and most body functions and activities (Dobkin 2004; Wiles et al. 2002).

While satisfaction increased in the first three months, it improved only slightly between the post-acute and chronic phases. During this period, patients recovered roles and abilities and were confronted with more demanding daily activities and life situations. Patients thus likely changed their perspectives of performance in activities and life situations, reducing
the degree of improvement in satisfaction between the post-acute and chronic phases (Ljunberg et al. 2001).

The responsiveness of the SATIS-Stroke questionnaire was also investigated with an individual approach. Our results corroborate the dominant pattern of satisfaction improvement (82% of the sample) between the acute and post-acute phases shown in the global approach. In contrast to the global approach, no dominant pattern emerged between the post-acute and the chronic phases: as shown on Figure 2, 58% of the sample reported an improvement and 40% reported a decrease in satisfaction. However one cannot reject that a significant change in satisfaction could appear between the post-acute and chronic phase in a larger sample of patients. The global approach was useful in our study to describe the change in satisfaction from the acute to the post-acute phases. Nevertheless, since this approach showed no pattern from the post-acute to the chronic phase, the individual approach was essential to understand and explain the decreased rate of satisfaction improvement. Therefore, this patient-focused approach better apprehended individual environmental factors and patient needs that hindered or facilitated satisfaction improvement. Indeed, the important change for each patient may not have had the same significance as for the sample as a whole (Beaton et al. 2001; Cella et al. 2002). The individual approach thus provides clinicians an alternative method of drawing conclusions from sample results at the patient level.
The “small improvement” observed in the MCID corresponded to a large change in the ERES. The MCID “small deterioration” corresponded to a moderate change in the ERES. However, the ERES method remains a theoretical method based upon the distribution of persons and as the observed $\frac{1}{2}$ SD in our study are equal to 0.56, 0.46 and 0.67, this method does not lead to false conclusions. This means that greater changes in satisfaction were necessary to detect clinically relevant improvement over time than clinically relevant deterioration with the SATIS-Stroke instrument. Therefore, in future study, the sample size required given reported size effects of 0.76, 0.42 and 1.12 would be respectively of 25, 76 and 11 patients. Nevertheless, some caution is necessary to interpret these results because the MCID of the SATIS-Stroke questionnaire (ICF activity and participation domains) was calculated on the basis of a perceived global functional status (only ICF activity domain).
Chapter 3

Satisfaction with activity and participation and its relationships with body functions, activities, and environmental factors in stroke patients

Abstract

Objectives: To report the body functions, activities, and participation of stroke patients and to investigate the relationships over time with the patients’ perceived satisfaction with their level of activity and participation.

Design: Descriptive

Setting: Hospital, home.

Participants: Stroke patients (N = 45; mean age ± SD, 69 ± 10.7 y) assessed by the same examiner.

Main outcome measures: The Stroke Impairment Assessment Set (SIAS) was used to measure body functions, the Mini Mental State Examination (MMSE) was used to measure cognitive level, and the Depression subscale of the Hospital Anxiety and Depression Scale (HADS) was used to measure mood level. The ABILHAND and ABILOCO scales were used to measure activity, and the SATIS-Stroke questionnaire was used to measure satisfaction with activities and participation. Social and physical environmental factors were assessed by the WHO’s checklist©. Patients were assessed during the acute (1 week), post-acute (three months), and chronic (six months) phases after stroke onset.
Results: Significant changes were observed over time in stroke body functions, cognitive status, manual and locomotion abilities, and satisfaction with activity and participation. At one week, satisfaction with activity and participation was not related to any body functions, activities, or environmental factors. At three months, manual ability was the only variable that was significantly related to satisfaction. During the chronic phase, manual ability and body functions were the best predictors of the stroke patient’s perceived satisfaction. However, this combination of factors predicted only 43% of the variation in the SATIS-Stroke measures.

Conclusions: Satisfaction with activity and participation cannot simply be inferred from body functions and activities, since it depends on complex interactions between functional, personal, and environmental factors.

Abbreviations

CVA .........................................................: Cerebrovascular disease
ADL..........................................................: Activity of Daily Living

Key words: ICF, participation, activity, satisfaction, stroke

Published in Archive of Physical Medicine and Rehabilitation as:
Bouffioulx E., Arnould C., Thonnard JL. Satisfaction with activity and participation and its relationships with body functions, activities, or environmental factors. In press
3.1. **Introduction**

Stroke is a principal cause of long-term disability in industrialized countries (Bonita 1992) and is the third most common cause of death (Baert Isle et al. 2008; Laloux 2003). The impact of stroke on patients’ functioning may be measured using the International Classification of Functioning, Disability, and Health (ICF) (World Health Organization 2001). The ICF adopts a patient-focused approach. Depending on the severity and location of the brain lesion(s), stroke may affect three separate, but related, functional dimensions: the body dimension (body functions and structures), the individual dimension (activity), and the social dimension (participation). Body functions are the physiological or psychological functions of the different body systems, and body structures are the anatomic parts of the body. Activity is the patients’ ability to execute tasks or actions. Participation is the patients’ involvement in life situations and the fulfillment of expected social roles (e.g. being a spouse, parent, workers, and friend), considering their age, sex, and the society and culture in which they live. Disregarding the individual and social dimensions during interventions may lead to inappropriate long-term rehabilitation, especially when patients return to their communities (Cardol et al. 2001).

Stroke recovery is largely recognized as a complex process (Dowswell et al. 2000), and the time since onset influences this recovery (Jorgensen et al. 1995). During the first six months, patients are generally confronted with various environments and each ICF dimension may change over time.
Several instruments have been developed to measure the activities and participation level of stroke patients. Such instruments assess a variety of parameters, including the degree of a patient’s performance in activities and life situations, the degree of assistance required, and the experienced difficulty. Satisfaction perceived by stroke patients in their experience in activities and life situations, independent of their actual performance, is rarely considered. In a patient-focused approach, it is important to measure satisfaction. Indeed, well-being can be defined as an individual’s satisfaction with his or her ability to do what he or she wants. A patient may experience satisfaction despite the need for assistance and/or in the presence of disabilities. For instance, a person may feel satisfaction when s/he has an opportunity to make a favorable choice according to his or her lifestyle. In a previous study (Bouffioulx et al. 2008), the SATIS-Stroke questionnaire was developed as a satisfaction measure of the activity and participation of stroke patients in their real-life environments. The SATIS-Stroke scores have been transformed into unidimensional and linear satisfaction measures using the Rasch measurement model (Rasch 1960).

According to the ICF, changes in one dimension (body functions, activities, participation, or environmental factors) have the potential to influence and modify one’s perceived satisfaction, but not always in a predictable, unequivocal manner (Arnould et al. 2007). Environmental and personal contextual factors can also facilitate or hinder patients’ functioning at the body, individual, or social levels. Although several studies have investigated the relationships between impairments and activities (Barbier et al. 2003; Caty et al. 2009; Penta et al. 2001), none to our knowledge have examined
the relationships between these dimensions and satisfaction, or changes over time in relationships between satisfaction and the other ICF dimensions.

The objectives of this study were to report the body functions, activity, and environmental factors in stroke patients during the acute, post-acute, and chronic phases and to investigate their relationships over time with patients’ perceived satisfaction with their activity and participation.

3.2. Patients and Methods

3.2.1. Subjects

This study was approved by the Medical Ethics Committee of the Université catholique de Louvain, Belgium. Patients gave written informed consent before the evaluations. The participants were recruited from a sample of adult patients admitted to Belgian stroke units between March 2007 and September 2008, who had a primary diagnosis of stroke or cerebrovascular accident (CVA). Eligible stroke patients were identified by reviewing the unit’s weekly admission records.

To be included in this study, the subjects had to present with a confirmed, eligible stroke as defined by the WHO: “rapid onset of vascular origin reflecting a focal disturbance of cerebral function, excluding isolated impairments of higher function and persisting longer than 24 hours” (World Health Organization 1983). No other confirmatory information (i.e., brain scans) was used to confirm the stroke diagnosis. Subjects were excluded if
they: (a) had stroke onset more than 8 days prior to admission, (b) were unable to care for themselves prior to their stroke, (c) had a stroke due to a subarachnoid hemorrhage, (d) were not expected to survive for at least 6 months, or (e) were lethargic, obtunded, or comatose, or (f) were aphasic. Sixty-three patients were originally recruited. Between the acute and post-acute phases, 11 patients chose to discontinue their participation and an additional 7 patients dropped out between the post-acute and chronic phases. Hence a total of 45 stroke patients (29 men and 16 women) with a mean age of 69 y (SD = 10.7 y) were assessed by the same examiner and included in the study. The sample description is provided in Table 1.

Table 1: Sample description (n = 45)

<table>
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<td><strong>Age (years), mean (range)</strong></td>
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<td><strong>Social status n</strong></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>28</td>
</tr>
<tr>
<td>Unmarried</td>
<td>17</td>
</tr>
</tbody>
</table>

CVA: Cerebrovascular Accident
3.2.2. Procedure

All 45 patients were followed from the onset of stroke until six months after stroke. Stroke survivors are typically described as going through the following phases: (i) acute phase (one week after the CVA onset), (ii) post-acute phase (three months after the CVA onset), and (iii) chronic phase (six months after the CVA onset). The patients received instructions on how to fill out the questionnaires and were tested individually in a quiet room. Patients who could not write were assisted with pictograms representing the responses’ scale.

1. Instruments

The ICF model (World Health Organization 2001) was used as a conceptual framework to assess the functioning of the stroke patients. The patient’s satisfaction with activity and participation, as well as other ICF dimensions, were assessed at each of the three aforementioned phases. Moreover, environmental factors were assessed following discharge at three and six months after stroke onset.

Assessment of body functions

Various aspects of stroke impairments were measured by the Stroke Impairment Assessment Scale (SIAS), including motor function, tone, sensory function, range of motion, pain, trunk function, visuospatial function, and speech function. All 22 SIAS items were rated from 0 (severely impaired) to 3 (normal), except for the motor function items which were rated from 0 (severely impaired) to 5 (normal). SIAS total scores range from 0
(severely impaired) to 76 (normal) corresponding to the summation the individual item scores (Chino et al. 1994) (Chino N et al. 1995).

Cognitive function was measured by the Mini Mental State Examination instrument (MMSE) (Folstein et al. 1975). The MMSE investigates an individual’s orientation, attention, calculation, recall, language, and motor skills. The total MMSE score ranges from 0 (severe cognitive impairment) to 30 (normal).

Mood was measured by the Hospital Anxiety and Depression Scale instrument (HADS) (Zigmond & Snaith 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.

Activity assessment

Walking ability was measured with the 13-item ABILOCO questionnaire (Caty et al. 2008). This instrument was validated previously using a Rasch analysis (Caty et al. 2008) in a sample of stroke patients and found to possess good psychometric qualities (validity, reliability, linearity, unidimensionality). This questionnaire measures “the walking ability of adult stroke patients by focusing on the activity domain of the ICF” (Caty et al. 2008). The 13 locomotor items in the questionnaire were rated by stroke patients themselves on a two-level scale (0: Impossible; 1: Possible).

Manual ability was measured with the 23-item ABILHAND questionnaire, which measures adults’ “capacity to manage daily activity
requiring the use of hands and upper limbs, whatever the strategies involved" (Penta et al. 2001). This instrument was validated previously by a Rasch analysis in a sample of stroke patients and found to possess good psychometric qualities (validity, reliability, linearity, unidimensionality). Twenty-three activities were rated by stroke patients themselves on a three level-scale (0: Impossible; 1: Difficult; 2: Easy).

Satisfaction assessment

Perceived satisfaction in the activity and participation dimension was measured using the 36-item SATIS-Stroke questionnaire (Bouffioulx et al. 2008), which was validated previously by a Rasch analysis allowing changes over time to be objectively quantified on a linear scale. The patients were asked to report their perception on a four-level scale (0: Very Dissatisfied; 1: Dissatisfied; 2: Satisfied; 3: Very Satisfied).

Environmental factors assessment

Environmental factors were assessed using the WHO’s ICF checklist (World Health Organization 2003) and included the patients’ social environment (human assistance) and physical environment (technical assistance). The eight items shown in Table 2 were selected. Four items were related to support and relationships and four items were related to products and technology. For each item, the patients were asked to answer whether the human or technical aid was absent or present on a two-level scale (0: Absence; 1: Presence).
Table 2: Requirements for human and technical aids during the post-acute and chronic phases

<table>
<thead>
<tr>
<th></th>
<th>Three months*</th>
<th>Six Months*</th>
<th>McNemar Test</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Human Aids</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Closed family assistance</td>
<td>89</td>
<td>67</td>
<td>0.03</td>
</tr>
<tr>
<td>Professional assistance</td>
<td>56</td>
<td>67</td>
<td>0.44</td>
</tr>
<tr>
<td>Friends assistance</td>
<td>11</td>
<td>11</td>
<td>1.00</td>
</tr>
<tr>
<td>Personal assistance</td>
<td>07</td>
<td>07</td>
<td>1.00</td>
</tr>
<tr>
<td><strong>Technical Aids</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Technical aids for walking</td>
<td>29</td>
<td>44</td>
<td>0.17</td>
</tr>
<tr>
<td>Technical aids for Activity Daily Living</td>
<td>47</td>
<td>38</td>
<td>0.29</td>
</tr>
<tr>
<td>House adaptations</td>
<td>16</td>
<td>16</td>
<td>1.00</td>
</tr>
<tr>
<td>Technical aids for communication</td>
<td>09</td>
<td>09</td>
<td>1.00</td>
</tr>
</tbody>
</table>

* Percent

2. Statistical analysis

Descriptive statistics were used to determine the extent of the stroke patients’ body functions, activity, satisfaction with activity and participation, and requirements for human or technical assistance in their usual environment. A Friedman one-way repeated measure analysis of variance (ANOVA) by ranks was performed to detect changes in the stroke patients’ body functions over time. Subsequently, multiple pair-wise comparisons were computed using a Tukey test. A one-way repeated measures ANOVA was used to observe changes in the activity and participation of patients over time. Subsequently, multiple pair-wise comparisons were computed using the Holm-Sidak method. Changes in requirements for human and technical environmental aids were also investigated between the post-acute and chronic phases using McNemar’s test. Human and technical
environmental scores were computed for the presence of four human and four technical aids from the ICF checklist.

The strengths of the linear associations between the satisfaction measures and other ICF variables (SIAS, MMSE, HADS for body functions, and ABILOCO and ABILHAND for activity) were determined using Spearman or Pearson correlation coefficients, depending on the nature of the data. Spearman correlation coefficients were calculated to investigate the linear relationship between the perceived satisfaction measures and the environmental factors during the post-acute and chronic phases. Correlation coefficients were interpreted according to the Guilford rules (Guilford 1956). Excluding the environmental factors, all of the ICF variables that were found to be significantly related to patients’ satisfaction with their activity and participation in were included in a multiple linear forward stepwise regression to select the best independent predictors of satisfaction. The adjusted coefficient of determination, which considers the number of selected variables, was used to avoid overestimating the true predictive capacity of the regression equation. The alpha level of significance was fixed at 0.05 for all the statistical tests.

3.3. Results

The stroke patients’ body functions, activity, and satisfaction with their activity and participation during the acute, post-acute, and chronic phases are presented in Table 2. Significant changes were observed over time in
Body functions, as measured by the SIAS (chi-square = 10.01, 2 degrees of freedom (df), p = 0.007), and in cognitive status, as measured by the MMSE (chi-square = 77.25, 2 df, p < 0.001). For both measures, significant improvements were observed between the acute and post-acute phases, but not between the post-acute and the chronic phases. Depressive status tended to increase over time as measured by the HADS; no significant change was observed between the acute and post-acute phases, but a significant increase in depressive status was observed between the post-acute and chronic phases.

Manual and locomotion abilities tended to increase over time (manual ability: F = 11.21, p < 0.001; locomotion ability: F = 10.49, p < 0.001). A significant improvement in manual and locomotion abilities was observed between the acute and post-acute phases, but not between the post-acute and chronic phases. During the post-acute phase, patients were approximately 4 \( (e^{1.42}) \) to 5 \( (e^{1.57}) \) times more likely to succeed at performing a given manual or locomotor activity than during the acute phase. Meanwhile, during the chronic phase, stroke patients were 1 \( (e^{0.19}) \) to 1.5 \( (e^{0.52}) \) times more likely to succeed at performing a given manual or locomotor than during the post-acute phase.

Satisfaction with activity and participation tended to increase over time. Similar to the improvement in manual and locomotor abilities, there was a significant improvement in satisfaction with activity and participation between the acute and post-acute phases, but not between the post-acute and chronic phases. During the post-acute phase, patients were 3 times \( (e^{1.10}) \)
more likely to be satisfied with a given activity or life situation than during the acute phase. During the chronic phase, the patients were 1.5 \( (e^{0.51}) \) and 5 \( (e^{5.03}) \) times more likely to be satisfied by their activities and life situations than during the post-acute and acute phases, respectively.

The proportions of stroke patients using human and technical aids are presented in Table 3. During the post-acute phase, approximately 90% of the patients needed family assistance, and more than half of these patients required assistance from a health professional. Approximately 10% of the stroke patients received assistance from friends, and less than 10% received personal assistance. During the chronic phase, the stroke patients required significantly less family assistance than during the post-acute phase, but this assistance remained important for two-thirds of the patients. The patients were receiving more assistance from health professionals during the chronic phase than during the post-acute phase, but the difference was not significant between the two phases. Similar to the post-acute phase, the chronic stroke patients required less assistance from friends and personal assistants. During the post-acute phase, half of the patients required technical aids for their daily living activities, and 30% required technical aids for walking. Of the patients, 16% or less required house adaptations and communication aids. During the chronic phase, the stroke patients required more walking aids but fewer daily living activity aids than during the post-acute phase. However, there was no significant change in the requirement for technical aids between the two phases. Similar to during the post-acute phase, few chronic stroke patients required house adaptations or communication aids (≤15%).
| Table 3: Stroke patients' body functioning, activity, and satisfaction with activity and participation during the acute, post-acute, and chronic phases |
|--------------------------------------------------|----------------|----------------|
| One week vs. Three Months | Statistics | p-value |
| SIAS, median (InterQuartile range) | 38 (32-46) | 44 (38-50) | 46 (38-52) | q = 3.58 | < 0.05 |
| MMSE, median (InterQuartile range) | 21 (18-23) | 23 (19-25) | 24 (22-26) | q = 6.41 | < 0.05 |
| HADS, median (InterQuartile range) | 6 (5-8) | 6 (4-11) | 9 (5-12) | q = 0.60 | > 0.05 |
| ABILHAND, mean (± SD) logits | -2.463 (2.035) | -0.892 (1.897) | -0.707 (2.897) | t = 3.85 | < 0.001 |
| ABILOC, mean (± SD) logits | -2.730 (2.260) | -1.309 (1.889) | -0.790 (2.219) | t = 3.24 | < 0.001 |
| SATIS-Stroke, mean (± SD) logits | -1.191 (1.435) | -0.090 (1.222) | 0.424 (1.804) | t = 0.45 | 0.65 |

SIAS: Stroke Impairment Assessment Scale
MMSE: Mini Mental State Examination
HADS: Hospital Anxiety Depression Scale
q = Tukey Test; t = Holm-Sidak test

Human functioning impairments

<table>
<thead>
<tr>
<th>Activity and Participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABILHAND, mean (± SD) logits</td>
</tr>
<tr>
<td>ABILOC, mean (± SD) logits</td>
</tr>
<tr>
<td>SATIS-Stroke, mean (± SD) logits</td>
</tr>
</tbody>
</table>

HADS: Hospital Anxiety Depression Scale
MMSE: Mini Mental State Examination
SIAS: Stroke Impairment Assessment Scale
q = Tukey Test; t = Holm-Sidak test
Table 4 presents the relationships between the patients’ satisfaction with activity and participation and their body functions and activity over time. No significant relationship was observed one week after CVA onset. At three months, manual ability was the only variable that was significantly, though weakly, related to the patients’ perceived satisfaction with their activity and participation (Guilford 1956). At six months, body functions (as measured by the SIAS), and manual and locomotor abilities were significantly and moderately related to satisfaction while cognitive status was significantly, though weakly, related to satisfaction. No significant relationship was found between mood status and satisfaction.

<table>
<thead>
<tr>
<th>Human functioning</th>
<th>One week</th>
<th>3 months</th>
<th>6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impairments</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SIAS</td>
<td>$p = 0.24$</td>
<td>$p = 0.16$</td>
<td>$p = 0.66$</td>
</tr>
<tr>
<td>MMSE</td>
<td>$p = 0.11$</td>
<td>$p = 0.15$</td>
<td>$p = 0.36$</td>
</tr>
<tr>
<td>HADS</td>
<td>$p = 0.22$</td>
<td>$p = -0.20$</td>
<td>$p = 0.10$</td>
</tr>
<tr>
<td>Activities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ABILHAND</td>
<td>$r = 0.23$</td>
<td>$r = 0.34$</td>
<td>$r = 0.66$</td>
</tr>
<tr>
<td>ABILOCO</td>
<td>$r = 0.03$</td>
<td>$r = -0.12$</td>
<td>$r = 0.41$</td>
</tr>
</tbody>
</table>

$r =$ Pearson correlation coefficient; $p =$ Spearman correlation coefficient

SIAS = Stroke Impairment Assessment Set; MMSE = Mini Mental Test Examination; HADS = Hospital Anxiety Depression Scale

A multiple linear forward stepwise regression was not performed on the acute phase data since there was no significant relationship between satisfaction and the other ICF variables. During the post-acute phase,
manual ability was found to account for only 12% of the variance observed in the SATIS-Stroke measures. During the chronic phase, manual ability was the strongest predictor of perceived satisfaction, and it accounted for 35% of the variance. Body functions, as measured by the SIAS, served as the second best independent predictor of perceived satisfaction and accounted for an additional 8% of the variance. The addition of other ICF variables did not substantially improve prediction of satisfaction (<3% improvement). The following regression equation was obtained by the forward stepwise method:

\[
\text{perceived satisfaction} = 0.33 \times (\text{manual disability as measured by ABILHAND}) + 0.07 \times (\text{physical impairments as measured by the SIAS}) - 2.66.
\]

Manual ability and stroke body functions combined predicted 43% of the variance in the SATIS-Stroke measures.

The combined influence of manual ability and SIAS body functions on satisfaction measures during the chronic phase is summarized in Figure 1. The patients with both a high manual ability (ABILHAND > -0.35 logits, using the mean ABILHAND measures as the cut-off) and a high level of body functions (SIAS > 46 using the median SIAS scores as cut-off) had the highest perceived satisfaction with activity and participation (Median: 1.77 logits; Interquartile range: 0.93–2.93 logits). The 12 patients who had either low manual ability measures associated with a high level of body functions or high manual ability measures associated with a low level of body functions had a lower perceived satisfaction with their activity and participation (Median: 0.24 logits; Interquartile range: -0.69–1.48 logits). Finally, the 16 stroke patients with both low manual ability measurements and low levels of body functions had the lowest perceived satisfaction.
measures (Median: -0.53 logits; Interquartile range: -1.38–0.07 logits). The Kruskal-Wallis test confirmed that the combined influence of manual ability and body functions was significantly related to perceived satisfaction with activity and participation (p < 0.001).

Figure 1: Box plots showing the perceived satisfaction with activity and participation measures distribution of stroke patients according to the presence of high or low level of manual ability measure and high or low level of body functions. Solid dots indicates the 5% and 95% outliers; vertical bars outside the box indicate the 10% and 90% limits; box indicates the 25 and 75% limits (i.e. the interquartile range); and the vertical line inside the box indicates the median of the distribution.

During the post-acute phase, no significant relationship was observed between the perceived satisfaction with activity and participation and the need for human (\( \rho = 0.20, \) p-value = 0.20) or technical aids (\( \rho = -0.07; \) p-value = 0.66). During the chronic phase, a significant relationship was observed between perceived satisfaction and the need for human assistance.
(ρ = 0.45, p-value = 0.02), but not between perceived satisfaction and use of technical aids (ρ = -0.20, p-value = 0.19).

### 3.4. Discussion

In this study, we examined perceived satisfaction with activity and participation and its relationship with ICF dimensions in 45 stroke patients during the acute, post-acute, and chronic phases following stroke. In most cases, no significant relationships were observed among physical impairment, activity limitations, and perceived satisfaction during the acute and post-acute phases. In the chronic phase, manual ability and body functions were the best independent predictors of patients’ perceived satisfaction with activity and participation; however, these factors only predicted 43% of the variance.

During the acute phase, no significant relationship was observed between perceived satisfaction with activity and participation and the different ICF dimensions. Indeed, in the acute phase, patients are critically ill and frequently bedridden with brief standing and ambulatory periods (Mayo et al. 1999). During hospitalization, stroke patients are rarely confronted with activities of daily living (ADL) and the variety of life situations that exist in their home and social environments. Hospital health professionals aim to help patients recover losses of body functions and meet their basic needs, such as washing themselves. This situation is not necessarily satisfying for patients. The perceived satisfaction with the activity and participation
measured in the stroke unit probably results from the patients’ perceived difference between their actual and previous health conditions. This difference is probably explained by the absence of any relationships among the body functions, the individual ICF dimensions, and the patients’ perceived satisfaction with activity and participation.

At three months, all of the ICF variables, except mood status (Ostir et al. 2008), were enhanced indicating that the patients’ health statuses improved along with increases in their perceived satisfaction. In most cases, there were no significant relationships observed between the patients’ perceived satisfaction and the other ICF dimensions. Only manual ability was significantly related to perceived satisfaction, but this relationship was weak. Hospital discharge is a critical stage in the rehabilitation of stroke patients (Fjaertoft et al. 2003). Frequently, patients encounter difficulties in transferring the skills they learned in the hospital to their home environments (Corr et al. 1995; Forster et al. 1992; Ma HJ et al. 1999). Indeed, at home, patients will be confronted with increasing challenges in achieving their ADL. During the post-acute phase, 89% of the patients received close family assistance to achieve their daily activities, and 60% of the patients benefited from the assistance of health professionals. In addition to the patients requiring human aids, 50% of the patients used technical aids for ADL. It is well known from the literature that achieving independence in ADL requires good upper limb functioning (Henderson 1995). Achieving ADL without help requires more effort and time from the patients even though the patients have a reduced energy capacity. This observation may explain why patients with high manual ability are more likely to be satisfied in their activities and
life situations than those with low manual ability. Manual ability accounts for 12% of the variance observed in the SATIS-Stroke measures, highlighting the importance of having good manual ability in achieving satisfaction with their performance in ADL.

During the chronic phase, the patients’ functioning did not improve significantly relative to the post-acute phase. Only depressive status increased significantly, a finding which is consistent with prior findings in the literature (Hackett et al. 2005; Herrmann et al. 1998; Kwok et al. 2006; Paolucci et al. 1999; Parikh et al. 1990). Contrary to the post-acute phase, perceived satisfaction with activity and participation during the chronic phase seems to reflect the combined effect of the ICF dimensions. Indeed, satisfaction correlated moderately with body functions, and correlated weakly with cognitive functional level. Significant moderate relationships were also observed between perceived satisfaction and manual and locomotion abilities. Moreover, a significant moderate relationship was found between patients’ perceived satisfaction and the use of human aids. The environmental analysis showed that, in the chronic phase, family assistance decreased in favor of assistance from health professionals, but this change was not significant relative to the post-acute phase. This observation suggests that if family assistance remains important, health professionals must ensure that the activities prescribed are embedded in everyday routines, such that they are meaningful for the patients.

During the chronic phase, manual ability, which accounted for 35% of the variance, was the factor with the strongest association with perceived
satisfaction. It seems that perceived satisfaction with activity and participation is more closely associated with upper limb functioning than lower limb functioning. Body functions, as measured by the SIAS, only accounted for an additional 8% of the variance. This finding reinforces the fact that satisfaction during the chronic phase results from the interactions of many components. Although the combination of manual ability and stroke body functions was significantly related to satisfaction, it only predicted 43% of the variance in SATIS-Stroke measures, consistent with the literature (Labi et al. 1980; Niemi et al. 1988). This finding seems to reflect the fact that the expected course of recovery (except for anterior cerebral artery stroke) wherein upper extremities are more affected initially and show more variability in recovery during follow-up (Beebe 2009; Higgins et al. 2005). As suggested by the ICF, several contextual factors, including personal factors (e.g. cognitive status, motivation, and adaptability) and environmental factors (e.g. heath services, financial support, and patients’ habits) may facilitate or hinder perceived satisfaction.

In our study, a moderate significant relationship was observed between satisfaction and the use of human aids. Several authors reported that social support was among the most robust and consistent predictors of post-stroke activities (Kwakkel et al. 1996). Therapists should identify the contextual factors that can be changed to facilitate ADL. However, it is important to note that some contextual factors are difficult to modify (e.g. societal attitudes, patients’ incomes, and community facilities) (Stucki et al. 2003). Thus, when planning a rehabilitation intervention, it is necessary to address the contextual factors that are easily modifiable and have the greatest potential
to improve patients’ satisfaction (Stucki et al. 2003). In the future, it would be interesting to investigate the relationships between satisfaction with activity and participation and contextual factors more precisely than in the present study by using a valid measure, such as the Measure of the Quality of the Environment (Fougeyrollas P et al. 1997).

The present study was limited by its cross-sectional nature and the fact that causality could not be determined using correlation coefficients or multiple linear regression analysis. As a result, we cannot state that 43% of the variance observed in the satisfaction measures results directly from manual ability and body functions. Prospective studies would therefore be useful in determining how changes in manual ability and body functions influence patients’ satisfaction. 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. The potential ceiling effects of the MMSE should also be mentioned here. Moreover the exclusion of aphasic patients could have resulted in an underestimation of the proportion of stroke patients who could benefit from communication aids. In the future, it would be useful to investigate social participation in terms of level of accomplishment.
3.5. Conclusion

Stroke patients’ satisfaction with activity and participation cannot simply be inferred from body functions and activities, since it depends on complex interactions between functional, personal, and environmental factors. Our results stress the importance of considering and measuring patient satisfaction, since it is not simply the integration of body functions and activities.
Discussion and Conclusion

The purposes of this study were as follows: (1) to validate a new scale of satisfaction with activities and participation; (2) to investigate the responsiveness of this scale; and (3) to investigate the relationships between the satisfaction with activity and participation and other dimensions of the ICF model. Several instruments have been developed to measure activities and participation in patients with disabilities (Cardol et al. 2002a; Gandek et al. 2007; Jette et al. 2002; Noreau et al. 2004). To our knowledge, few instruments actually measure the satisfaction perceived by stroke patients in their experience in activities and life situations, especially in the French language. With a patient-focused approach, it is important to measure satisfaction so that the rehabilitation process meets the needs that are essential to the patient’s well-being (Larsson et al. 2005).

Several studies have examined the effect of stroke consequences (e.g., physical impairments and mental status) on satisfaction with community reintegration (Carter et al. 2000; Carter et al. 1997; Clarke et al. 1999; Ostir et al. 2005). Health care professionals are becoming increasingly aware that recovery after stroke cannot be measured purely by one’s functional abilities. Patients with stroke have a low level of satisfaction with community reintegration after their discharge from the hospital and return to the community (Bethoux et al. 1999; Clarke et al. 1999). A patient’s self-perceived participation in community activities and satisfaction with his/her

Chapter 1 described the use of the Rasch model to develop and validate a new scale of perceived satisfaction with activity and participation in adults with chronic stroke. The original 84-item version of the SATIS-Stroke questionnaire was developed in French, and its purpose was to validate the satisfaction measure in the actual environment experienced by chronic stroke patients. This scale also is currently available in English. From the original pool of 84 items, 36 items were retained for the final SATIS-Stroke questionnaire, which conformed with the ICF dimensions and the ICF Core Set for Stroke (Geyh et al. 2004). The final items defined a unidimensional and linear scale according to the Rasch model.

The content of the hierarchical scale indicated that the more-satisfactory items were predominantly related to communication and interpersonal relationships, and less-satisfactory items were related to mobility and self-care. This finding suggests that physical limitations and functional dependence may decrease the satisfaction and well-being experienced by patients in their activities and life situations. Life satisfaction often was related to age, employment status, income, and marital status, as well as severity of disability, among other variables (Mehnert et al. 1990). A significant relationship was found between the results of the SATIS-Stroke questionnaire and age, consistent with previous studies that showed a
A significant link between age and the occurrence of a handicap situation (Desrosiers et al. 2006; Desrosiers et al. 2002).

The satisfaction measure is an advantageous construct because of its self-report nature and the fact that satisfaction is an important aspect of well-being. The use of life satisfaction as an outcome for assessing change over time or between groups is a challenge that has been studied in individuals with stroke relative to their physical and cognitive functional capabilities (Granger et al. 1993) and psychosocial function (Astrom et al. 1992). Because satisfaction measures are completed from the perspective of the individual, the measurement of this construct can be modified by psychological phenomena such as coping and adaptation. A previous study found that the satisfaction measure was significantly lower among nursing home residents than among home residents, probably because their level of satisfaction depends on how the nursing assistants meet their needs. This information is valuable, because the patient’s opinion of their satisfaction is often different from that of their social environment (Segal et al. 1996).

Stroke comes on suddenly, and it is followed by a recovery process that is most rapid during the first 5 weeks but may continue until 6 months poststroke (Ahmed et al. 2004). The recognition of the importance of functional outcomes in stroke has led to a shift from the use of measures of pathology and impairment to the use of disability instruments. Disability instruments measure a patient’s ability to perform basic ADLs (i.e., in terms of mobility and self-care) and/or extended ADLs (e.g., housework) (Weisscher et al. 2010).
Because most individuals with stroke experience changing physical health for several months, it is useful to study how well changes in the satisfaction measure over time reflect the evolution of the perceived satisfaction. This change in bodily health experience may be related to the response shift theory (Schwartz et al. 2007). This theory is defined as changes in a person’s self-evaluation due to changes in internal standards or recalibration of the measurement scale; changes in the definition or conceptualization of the construct; and/or changes in values or in the prioritization of domains within the construct (Mayo et al. 2009).

Chapter 2 focused on the assessment of changes in internal standards after stroke by examining changes in the patient’s perceived satisfaction with activity and participation, among a sample of adult stroke patients in the acute, postacute, or chronic phase. The patient’s perspective of their functioning, determined in part by self-completed questionnaires of health and functional status, was an important component of the outcome assessment. Thus, it was important to investigate the responsiveness of the satisfaction scale.

A patient-focused approach showed that satisfaction significantly increased between the acute and the postacute phases, although no significant change in satisfaction was observed between the postacute and chronic phases. While satisfaction increased in the first 3 months, it improved only slightly between the postacute and chronic phases.

The responsiveness of the SATIS-Stroke questionnaire also was investigated with individual and global approaches. The individual approach
corroborated the dominant pattern of satisfaction improvement between the acute and postacute phases shown in the global approach. In contrast to the global approach, no dominant pattern emerged between the postacute and chronic phases. The individual approach was essential to explain the decreased rate of improvement in satisfaction. Therefore, the patient-focused approach revealed individual environmental factors and patient needs that hindered or facilitated satisfaction improvement. Indeed, the important change for each patient may not have had the same significance as that for the whole sample (Beaton et al. 2001; Cella 2002).

The changes that occurred over time poststroke (or as the result of an intervention) might have affected the patient’s internalized standard of judgment of what value on a scale reflects excellent or poor levels of health-related QoL. Although a response shift is a natural way by which individuals who are confronted with a serious illness adapt and cope with changes in physical health, it influences objective measures of change of satisfaction. It may be difficult to distinguish objective changes due to the illness or an intervention from the response shift. Conventional comparisons of mean scores before and after an elapsed period of time do not differentiate between these types of change (Ahmed et al. 2004). Satisfaction is a personal judgment provided by the individual and is a global construct that can represent the individual’s overall judgment of his or her perspective.

This shift in focus from impairment to participation and satisfaction would induce a response shift as stroke patients learn to value what they can do despite impairments rather than focusing on the limitation itself.
Evaluating interventions is complicated by spontaneous recovery, change in outcome emphasis, and response shift (Mayo et al. 2009). Thus, it was interesting to study the evolution of satisfaction after stroke onset (from the acute phase to the chronic phase) and its relationships with other dimensions of the ICF model.

In Chapter 3, we examined the perceived satisfaction in stroke patients during the acute, postacute, and chronic phases following stroke. In most cases, no significant relationships were observed among physical impairment, activity limitations, and perceived satisfaction during the acute and the postacute phases. In the chronic phase, manual ability and body functions were the best independently associated variables of the patients’ perceived satisfaction with activity and participation. No significant relationship was observed between the perceived satisfaction and the different ICF dimensions during the acute phase, probably because the patient’s perceived satisfaction arises from the perceived difference between their actual and previous health conditions.

At 3 months, all of the ICF variables except mood status (Ostir et al. 2008) were enhanced; this finding indicated that the patients’ health statuses improved along with increases in their perceived satisfaction. In most cases, no significant relationship was observed between a patient’s perceived satisfaction and the other ICF dimensions. Only manual ability was related significantly to perceived satisfaction, but this relationship was weak. During the chronic phase, the patients’ functioning did not significantly improve compared to the postacute phase. Only the depressive status significantly
increased. Satisfaction was moderately correlated to body functions and weakly correlated to cognitive functions. Significant moderate relationships also were observed between the perceived satisfaction and manual and locomotion abilities. The environmental analysis showed that, family assistance in the chronic phase decreased in favor of assistance from health professionals; however, this change was not significant compared to the postacute phase. During the chronic phase, manual ability was the strongest associated variable of perceived satisfaction, although the combination of manual ability and stroke body functions also was related significantly to satisfaction. As suggested by the ICF, several contextual factors, including personal factors (e.g., cognitive status, motivation, and adaptability) and environmental factors (e.g., health services, financial support, and patients’ habits), may facilitate or hinder the perceived satisfaction.

Many authors advocate greater implementation of subjective measures on the basis that the judgment of an individual with a disability is the ultimate determinant of whether his or her participation is adequate (Cardol et al. 1999; Hemmingsson et al. 2005). The continuum of the three studies showed that satisfaction with activity and participation may be a linear, unidimensional measure that is sensitive to change but is partially explained by the impairment, activity limitation, and facilitators/barriers of the environment.

The metric properties of SATIS-Stroke constitute an encouraging starting point for further investigation. The questionnaire is easy to administer and requires little time to complete (about 15 min). SATIS-Stroke
Discussion and Conclusion

appears to be precise enough to discriminate patients’ satisfaction levels and, presumably, to capture even subtle satisfaction changes over time. The item satisfactory level hierarchy must be invariant across cultures to obtain a cross-cultural measure of perceived satisfaction in patients with stroke. DIF tests, one feature of the Rasch model, are a suitable solution to this cultural equivalence condition (Smith 1992; Wright 1979). The scale focuses on the satisfaction of chronic stroke patients with their performance in activities and life situations.

**Study limitations**

Globally, this study had certain limitations, such as a small sample size, its cross-sectional nature, the absence of patients with cognitive impairments, and lack of larger demographic characteristics. In addition, other indicators have been integrated in the study design, such as the patient’s level of education or degree of impairment, to better describe the cohort in the study.

Researchers frequently perform sample size estimations from a power analysis perspective to have a reasonable probability of obtaining reliable parameter estimates that are statistically significant. Although the sample size for a scale construct represents the adequate population needed for the calibration of a well-constructed and well-targeted instrument (Linacre 1994; Wright 1996), the resulting sample size may be too small when split into subgroups (such as in the DIF) (Tristan 2006) to allow accurate interpretation. If the sample is small, then there is a low probability that a real difference will appear as a significant difference; significant differences are
more likely to be spurious with small samples than with large samples. Social sciences slowly are becoming aware of the problems associated with underpowered studies and their corresponding Type II errors, which can yield misleading results. In the present study, the sample size may have been too small to study the responsiveness of the scale. However, one cannot reject the hypothesis that a significant change in satisfaction could appear between the postacute and chronic phases in a larger sample of patients. Therefore, performing sample size planning solely for the purpose of obtaining accurate parameter estimates, not merely statistically significant ones, is highly recommended.

Because causality cannot be determined by correlation coefficients or multiple linear regression analysis for a cross-sectional study, this design may limit the descriptive study of a situation at one particular time. A cross-sectional study examines different variables in a population to describe the nature and incidence of disease at a particular point in time. It provides a snapshot of the current conditions, but does not explain the cause-and-effect linkages among their components or constituents. As a result, we cannot state that the percentage of the variance observed in the satisfaction measures resulted directly from the variables such as manual ability and body functions.

The exclusion of patients with cognitive deficits may not be entirely representative of all chronic stroke patients; therefore, the study cannot be generalized for patients with cognitive impairments, such as those in speaking, listening, reading, writing, and other nonverbal methods.
Participation in communicative situations is described as satisfactory when it is comfortable, easy, associated with a feeling of confidence or self-assurance, and when the outcome is successful (Yorkston et al. 2007). The exclusion of individuals with poor receptive language and communication skills could have led to an unequal representation of functional disability severities between the right and left hemisphere groups (i.e., through the exclusion of more severely impaired left hemisphere stroke patients), even if we had no difference in the responses of scale on the basis of the CVA side.

The potential ceiling effects of the MMSE should also be mentioned. When disabling conditions involve communication disorders, the potential for participation restrictions is especially high and distressing (Yorkston et al. 2007). Under this definition, the life situation reflects the notion that communication occurs within a social context of what is being communicated, where, when, why, and with whom. The exclusion of aphasic patients also could have resulted in an underestimation of the proportion of stroke patients who could benefit from communication aids.

Poststroke consequences, apparent or invisible, create a new reality (Rochette et al. 2006). In this context, it would also be interesting to investigate the satisfaction level of the caregivers. The satisfaction levels of caregivers and patients tended to differ in accordance with the affected side of the brain. Satisfaction with participation is closely related to personal goals and priorities and might better reflect an individual's perception of his/her optimal participation level. Indeed, it is possible that caregivers' satisfactions are lower when the duration of handicap is longer.
Discussion and conclusion

Perspectives

The three studies showed that the SATIS-Stroke questionnaire is promising for use in rehabilitation from stroke. The questionnaire possesses valuable psychometric properties, is sensitive, and could be translated into other languages through the use of forward and backward translations of the items. Studies on satisfaction with activity and participation in stroke patients could be performed at the European and international levels, and the results could be compared between different countries. It is the author’s hope that the SATIS-Stroke scale ultimately will be applied to evaluate satisfaction in other pathological states in adults, with the prospect of building a generic measure of adult patient satisfaction with activities and participation. However, future research is required to verify the responsiveness of SATIS-Stroke in evaluating acute and chronic stroke patients.

Therefore, prospective studies would be useful to determine how changes in manual abilities and body functions influence a patient’s level of satisfaction. One fundamental goal of rehabilitation is to improve the patient’s ability to manage daily activities and to achieve autonomous living. Therefore, it would be interesting to calibrate a scale to measure the stroke patient’s restriction of social participation in terms of the degree of participation in activities and life situations. This new Rasch-built scale would be constructed in accordance with the concept of condition-specific health-status measures, such as the core set defined by Geyh (Geyh 2004). It also would be interesting to compare the satisfaction level measured by SATIS-Stroke and the participation restriction measured with such new scale. This
comparison could confirm or reject the hypothesis that the satisfaction measure reflects the individual's perspective or whether his/her performance in activities and life situations meets his/her needs.

It also would be useful to investigate social participation in terms of the level of accomplishment. Patients likely changed their perspectives of performance in activities and life situations, thereby reducing the degree of improvement in satisfaction between the postacute and chronic phases (Ljunberg et al. 2001). Thus, greater changes in satisfaction over time were necessary to detect clinically relevant improvements than to detect deteriorations with the SATIS-Stroke instrument.

Finally, it would be interesting to investigate more precisely the relationships between satisfaction and contextual factors by using a valid measure, such as the Measure of the Quality of the Environment (Fougeyrollas et al. 1997).

Recommendations

Clinicians might decline to use this questionnaire ignoring the limitations of ordinal scores and the need for an objective measurement. Indeed, scoring patients on an ordinal rating scale is less complex than learning a statistical method that allows the conversion of ordinal total scores into linear measures. Thus, clinicians can use the patient's total score to predict rapidly the activities and life situations that are satisfactory or dissatisfactory for the patient. This tool can help them to establish goals and to track (on a linear scale) the satisfaction level of each patient throughout the rehabilitation
process, regardless of their gender, age, social status, place of residence, delay since stroke, and CVA side.

To help clinicians with the practical use of Rasch-built scales, a website has been developed that includes scoring sheets and routines that automatically provide the patient’s linear measures from his score responses (http://www.rehab-scales.org). This site also provides, after a user’s free registration, a report that includes both the patient’s measure expressed in logits and a figure (item map) that compares the expected score by the Rasch model and the patient’s observed score.

The therapist should attempt to identify the contextual factors that are crucial for the patients’ satisfaction and to find the contextual factors that can be changed to facilitate the achievement of activities and the fulfilment of life situations. Further research could identify which contextual factors influence activity limitations and participation restrictions in stroke patients to elucidate what can be changed to facilitate the achievement of daily activities (Law 1993; Stucki et al. 2002).

According to the ICF, stroke may affect three separate but related dimensions of functioning: body functions and structures, activities, and participation. Drawing distinctions between these dimensions, as proposed by the ICF, is far from being futile, because a problem may occur in one dimension but not in the others. Moreover, changes in one dimension may influence and modify the other dimensions but not always in a predictable unequivocal relationship (Arnould et al. 2007).
Environmental and personal contextual factors also can facilitate or hinder a patient’s functioning, or social level. Models of disabilities, such as the WHO model (WHO, 2001) and the Quebec model (DCP, 1998), hypothesize that environmental factors are crucial determinants of a person’s participation in ADLs (Fougeyrollas 1995; Teel et al. 1997). It may also be important to consider personal factors, which can predict adaptive or maladaptive behaviors (Gray et al. 2008). This recommendation is consistent with the perspective of the ICF that disability results from the interaction between a person’s health condition and contextual factors. To understand the person-environment relationship, one must know the person’s personal factors; the external context/environment that can be described and assessed objectively by an outsider (i.e., by using the ICF environmental factors classification); the person’s perceptions of his/her environment (as indicated by his/her own description); the process of interaction between these different elements; and the outcomes of disability at the body, person, and societal levels as defined in the ICF.

Additionally, therapists should identify the contextual factors that can be changed to facilitate ADLs. However, some contextual factors are difficult to modify (e.g., societal attitudes, patients' incomes, and community facilities) (Stucki et al. 2003). Thus, when planning a rehabilitation intervention, it is necessary to address the contextual factors that are easily modifiable and have the greatest potential to improve the patient’s satisfaction (Stucki et al. 2003).
Conclusion

The results of present research stress the importance of considering and measuring satisfaction *per se*. Satisfaction with activity and participation seems to represent a major goal in a long-term rehabilitation program and probably reflects better how the patient experiences his/her activity limitations and participation restrictions. However, the evaluating satisfaction is complex; satisfaction is not simply dependant of body functions and activities, because it depends on a variety of interactions between functional, personal, and environmental factors.
References


Andrich D. Application of a psychometric rating model to ordered categories which are scored with successive integers. Appl Psych Meas 1978b; 2:581-94.


Ashburn A. Physical recovery following stroke. Physiotherapy 1997; 83 (9):480-90.


Claesson L, Linden T, Skoog I et al. Cognitive impairment after stroke - impact on activities of daily living and costs of care for elderly


Fougeyrollas P, Noreau L, St-Michel G. Measure of the Quality of the Environment - version 1.0. Lac St-Charles, Quebec, Canada: CQCIDIH 1997.


Hankey G. Stroke: how large a public health problem, and how can the neurologist help? Arch Neurol. 1999; 56:748-54.


Juniper EF, Price DB, Stampone PA et al. Clinically important improvements in asthma-specific quality of life, but no difference in conventional clinical indexes in patients changed from conventional beclomethasone dipropionate to approximately half the dose of extrafine beclomethasone dipropionate. Chest 2002; 121 (6):1824-32.


Levasseur M, Desrosiers J, St-Cyr Tribble D. Do quality of life, participation and environment of older adults differ according to level of activity? Health Qual Life Outcomes 2008; 6:30.


Middel B, van Sonderen E. Statistical significant change versus relevant or important change in (quasi) experimental design: some conceptual and methodological problems in estimating magnitude of intervention-related change in health services research. Int J Integr Care 2002; 2:e15.


Perenboom RJ, Chorus AM. Measuring participation according to the International Classification of Functioning, Disability and Health (ICF). Disabil Rehabil 2003; 25 (11-12):577-87.


Sartorius N. The Quality of Life of Cancer Patients. Cross-Cultural Comparisons of Data about Quality of Life: a Sample of Issues. In:


Whitley Jr. BE. Principles of research in behavior science Mountain View, CA: Mayfield Publishing 1996.


Wright B, Linacre, JM,. Observations are always ordinal; measurement, however, must be interval. Arch Phys Med Rehabil 1989; 70:857-60.


Appendix I: French version of the SATIS-Stroke questionnaire

INSTRUCTIONS POUR LE QUESTIONNAIRE SATIS-STROKE

Le questionnaire SATIS-Stroke

Le questionnaire SATIS-Stroke est destiné à élaborer une mesure de la satisfaction perçue dans la réalisation des activités de la vie quotidiennes et la participation dans les différentes situations de vie par les patients. Les 36 items de SATIS-Stroke définissent une échelle de satisfaction valide, fiable, reproductible. SATIS-Stroke a été développé en utilisant le modèle de Rasch. Ce modèle permet de convertir les scores ordinaux en mesures linéaires localisées sur une échelle unidimensionnelle.

Procédures :

Le questionnaire SATIS-Stroke est administré sous forme d’interview ou rempli par le patient seul. Ce dernier doit estimer le niveau de satisfaction dans la réalisation des activités de la vie quotidiennes et la participation dans les différentes situations de vie. La perception est donnée :

♣ dans le mois qui précède le remplissage du questionnaire ;

♣ quelle que soit la stratégie utilisée ;

♣ quelles que soient les compensations employées.

Une échelle à quatre catégories de réponses est proposée aux patients pendant l’évaluation. Le patient exprime le niveau de satisfaction ou d’insatisfaction pour chaque item présenté, soit « Totalement insatisfait », « Insatisfait », « Satisfait » ou « Très satisfait ». Les items qui ne correspondent pas à son cadre de vie ou pour lequel il ne peut s’exprimer sont cotés « Je ne sais pas / Ne s’applique pas ». Pour chaque item, 5 réponses sont possibles :

- **Très insatisfait** : le patient exprime une profonde insatisfaction soit dans la réalisation de l’activité, quelle que soit la stratégie utilisée, soit par le fait de ne plus pouvoir la réaliser compte tenu des circonstances ;

- **Insatisfait** : le patient exprime une insatisfaction dans la réalisation de l’activité mais nuance sa perception de façon moins péjorative ;

- **Satisfait** : le patient exprime une satisfaction dans la réalisation de l’activité mais estime ne pas jouir de la pleine satisfaction compte tenu des circonstances ;

- **Très satisfait** : le patient exprime une complète satisfaction tant dans la réalisation, que dans la manière de la conduire.

Les instructions sont données aux patients en début de passation. Un maximum de cinq items est utilisé en guise d’entraînement pour aider le patient à comprendre chacune des catégories de l’échelle et utiliser, ainsi, toute l’amplitude de l’échelle des réponses. Aucune autre instruction ultérieure n’est nécessaire. L’examineur peut, cependant, répéter les instructions si le patient venait à exprimer des hésitations.

Ordre des activités :

Les activités du questionnaire SATIS-Stroke sont présentées dans un ordre aléatoire afin d’éviter un biais systématique. Il existe dix ordres aléatoires différents.

References
**SATIS-Stroke :** Une mesure de la satisfaction dans la réalisation des activités quotidiennes et la participation sociale

<table>
<thead>
<tr>
<th>Quel est votre niveau de satisfaction dans les situations de vie suivantes?</th>
<th>Très insatisfait</th>
<th>Insatisfait</th>
<th>Satisfait</th>
<th>Très satisfait</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participer à la préparation des repas ou des boissons à la maison</td>
<td></td>
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<tr>
<td>Utiliser couteau, fourchette, cuillère selon les circonstances</td>
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<tr>
<td>Participer à l'échange d'informations orales avec mon entourage</td>
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<tr>
<td>Se laver les cheveux en toutes circonstances</td>
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<tr>
<td>Se déshabiller et s'habiller à la toilette à la maison ou en dehors de celle-ci</td>
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<tr>
<td>Faire sa toilette intime selon les besoins</td>
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<tr>
<td>Avoir une continence urinaire à la maison et en dehors de celle-ci</td>
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<tr>
<td>Participer à des activités artistiques et culturelles (cinéma, théâtre, etc.)</td>
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<tr>
<td>Coopérer avec son entourage</td>
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<tr>
<td>Lire et comprendre un document en toutes circonstances</td>
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<tr>
<td>Utiliser le téléphone ou le GSM selon les besoins</td>
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<tr>
<td>Ecouter la radio et/ou la télévision selon mes besoins</td>
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<tr>
<td>Gérer ses revenus en toutes circonstances</td>
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<tr>
<td>Utiliser la monnaie et les billets en toutes circonstances</td>
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<tr>
<td>Se déshabiller en toutes circonstances</td>
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<tr>
<td>Faire respecter ses droits en toutes circonstances</td>
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<tr>
<td>Participer aux relations de couple en toutes circonstances</td>
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<tr>
<td>Prendre son bain ou sa douche selon les besoins</td>
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<tr>
<td>Atteindre les objets dans son espace immédiat</td>
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<tr>
<td>Prendre les vêtements dans l'armoire selon les besoins.</td>
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<tr>
<td>Quel est votre <strong>niveau de satisfaction</strong> dans les situations de vie suivantes?</td>
<td>Très insatisfait</td>
<td>Insatisfait</td>
<td>Satisfait</td>
<td>Très satisfait</td>
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<tr>
<td>21</td>
<td>Compléter des documents administratifs en toutes circonstances</td>
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<tr>
<td>22</td>
<td>Se déplacer à l’intérieur de son habitation selon les besoins</td>
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<tr>
<td>23</td>
<td>Se déplacer à l’extérieur de son habitation en toutes circonstances</td>
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<tr>
<td>24</td>
<td>Monter et descendre tous les étages de son habitation selon les besoins</td>
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<tr>
<td>25</td>
<td>Entrer et sortir de son habitation selon les besoins</td>
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<tr>
<td>26</td>
<td>Ouvrir et fermer les portes de son habitation</td>
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<td>27</td>
<td>Utiliser les espaces de rangement dans son habitation</td>
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<tr>
<td>28</td>
<td>Choisir les vêtements appropriés</td>
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<tr>
<td>29</td>
<td>Partager ses émotions</td>
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<tr>
<td>30</td>
<td>Être conscient de ce qui vous entoure</td>
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<tr>
<td>31</td>
<td>Exprimer ses envies à ses proches</td>
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<tr>
<td>32</td>
<td>Participer à des cérémonies (mariage, anniversaire, etc.)</td>
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<tr>
<td>33</td>
<td>Demander de l’aide en cas d’urgence</td>
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<tr>
<td>34</td>
<td>Gérer ses douleurs en toute circonstance</td>
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<td></td>
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<tr>
<td>35</td>
<td>Avoir une vie affective</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>36</td>
<td>Avoir une vie sexuelle</td>
<td></td>
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</tbody>
</table>
Appendix II: English version of the SATIS-Stroke questionnaire

INSTRUCTIONS FOR THE SATIS-STROKE QUESTIONNAIRE

The SATIS-Stroke questionnaire was developed as a measure of satisfaction with activities and participation as perceived by the stroke patient. It explores the most representative inventory life situations. The 36 items of the SATIS-Stroke questionnaire defined a valid, reliable and reproducible scale. SATIS-Stroke was originally developed using the Rasch measurement model. It allows converting ordinal scores into linear measures located on a unidimensional scale.

Procedures
The SATIS-Stroke questionnaire is administered on an interview basis (patients do not realize the activities) or self-administration. Patients are asked to estimate the satisfaction level in performing each life situation, when the activities/participation are done:
- In the month preceding the filling out the questionnaire;
- With other technical or human help (even if the patient actually uses help in daily life);
- Whatever the strategy used (any compensation is allowed).

During the evaluation, a 4-level response scale is presented to the patients. Patients are asked to rate their perception on the response scale as either "Very dissatisfied", "Dissatisfied", "Satisfied" or "Very satisfied". Activities or participation not attempted in the last month are not scored and are entered as missing responses (tick the question mark). For any activity the four potential answers are:
- **Very dissatisfied**: the patient expresses a deep dissatisfaction with the way it carries out the activity or socially takes part in the various life situations, whatever the strategy used, or the fact of not being able to carry it out taking into account the circumstances;
- **Dissatisfied**: the patient expresses a dissatisfaction with the way it carries out the activity or socially takes part in the various life situations, whatever the strategy used, or the fact of not being able to carry it out taking into account the circumstances;
- **Satisfied**: the patient expresses satisfaction in the achievement of the activity or socially takes part, but estimates not to enjoy the full satisfaction taking into account the circumstances;
- **Very satisfied**: the patient expresses a complete satisfaction in both the level of achievement, that of social participation.

The instructions are given to the patient only at the beginning of the test. Five items are used for training in order to help the patient in feeling each level of the rating scale and in using the whole amplitude of the response scale. The subsequent activities are neither preceded nor followed by any instruction. The examiner can repeat the instructions whenever the patient shows some hesitation in answering.

Activities order
The life situations of the SATIS-Stroke questionnaire are presented in a random order to avoid any systematic effect. Ten different random orders of presentation are used. The rater must select the next one of the 10 orders for each new assessment, no matter which patient is tested.
SATIS-Stroke: Satisfaction with activities and participation

**English Version**

<table>
<thead>
<tr>
<th>Patient</th>
<th>Date</th>
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</table>

<table>
<thead>
<tr>
<th>How are you <strong>satisfied</strong> in the performing of the following life situations?</th>
<th>Very dissatisfied</th>
<th>Dissatisfied</th>
<th>Satisfied</th>
<th>Very satisfied</th>
<th>?</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>Participating in food and drink preparation in all circumstance</td>
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<tr>
<td>02</td>
<td>Using knife, fork and spoon in all circumstance</td>
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<tr>
<td>03</td>
<td>Participating in spoken exchange of information with your entourage</td>
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<tr>
<td>04</td>
<td>Washing your hairs according to your needs</td>
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<tr>
<td>05</td>
<td>Undressing to use the toilet and redressing in your home or outside of this one</td>
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<tr>
<td>06</td>
<td>Making your personal hygiene according to your needs</td>
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<tr>
<td>07</td>
<td>Having an urinary continence in your home and outside of this one</td>
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<tr>
<td>08</td>
<td>Participating in arts and culture (cinema, theatre, etc.)</td>
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<tr>
<td>09</td>
<td>Co-operating with your entourage</td>
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<tr>
<td>10</td>
<td>Reading and understanding a document in all circumstance</td>
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<tr>
<td>11</td>
<td>Using telephone at home according to your needs</td>
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<td></td>
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<td>12</td>
<td>Listening to and looking at television according to your needs</td>
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<tr>
<td>13</td>
<td>Managing your incomes in all circumstance</td>
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<td>14</td>
<td>Using coins and banknotes in all circumstance</td>
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<td>15</td>
<td>Dressing and undressing in all circumstance and according to your needs</td>
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<td>16</td>
<td>Ensuring that your rights are respected</td>
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<td>17</td>
<td>Participating in spousal relationships</td>
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<td>18</td>
<td>Taking your bath or your shower according to your needs</td>
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<td>19</td>
<td>Reaching objects in your closely space</td>
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<td>20</td>
<td>Getting clothes out of the closet</td>
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<td></td>
<td>How are you <strong>satisfied</strong> in the performing of the following life situations?</td>
<td>Very dissatisfied</td>
<td>Dissatisfied</td>
<td>Satisfied</td>
<td>Very satisfied</td>
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<td>21</td>
<td>To supplement administrative documents in all circumstances</td>
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<td>22</td>
<td>Moving inside your home</td>
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<tr>
<td>23</td>
<td>Moving outside your home in all circumstance</td>
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<td>24</td>
<td>Climbing and going downstairs all stages in your home according to your needs</td>
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<tr>
<td>25</td>
<td>Entering and exiting your home according to your needs</td>
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<td>26</td>
<td>Opening and closing doors in your home</td>
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<td>27</td>
<td>Using storage spaces in your house</td>
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<td>28</td>
<td>Choosing appropriate clothes</td>
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<td>29</td>
<td>Getting in feeling across</td>
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<td>30</td>
<td>Being aware with what surrounds you</td>
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<td>31</td>
<td>Expressing oneself to someone</td>
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<td>32</td>
<td>Participating in ceremonies (marriage, gathering family, etc.)</td>
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<td>33</td>
<td>Asking for help in an emergency situation</td>
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<td>34</td>
<td>Managing your pains in all circumstance</td>
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<td>35</td>
<td>Maintaining emotional relationships</td>
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<td>36</td>
<td>Having a sexual relationship with another</td>
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