Evaluation of autonomies in the severely brain injured: the Progression of Autonomies Scale

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Summary

The aim of this study was to validate the Progression of Autonomies Scale (PAS) for the evaluation of autonomies in severe acquired brain injury patients. The PAS design is based on a model of progressive recovery of autonomies and is organized in three domains (Personal, Domestic and Extra-domestic). Scores assigned range from zero to three. The PAS items gather information about the patient's perception and awareness of his/her disability(ies) on admission and perception of his/her improvement at the end of a rehabilitation process.
The PAS was administered to 127 inpatients on admission to and at discharge from a rehabilitation program. All 127 inpatients, recruited in a prospective multicenter study, completed the rehabilitation program. The statistical analysis identified a total of 38 items to be retained in the PAS, out of an initial 82 items. The results provide evidence of the validity and reliability of the PAS in its final version.

KEY WORDS: acquired brain injury, autonomy, cognitive rehabilitation, evaluation scale.

Introduction

It is well known that acquired brain injury (ABI) commonly causes lifelong impairments of physical, cognitive, behavioral and social functions, resulting in different profiles of disability (Jennet et al., 1981; Ben-Yishay and Diller, 1993; Prigatano, 1999; Sohlberg and Mateer, 2001; Ponsford, 2004; Lannoo et al., 2011). The recovery of optimal levels of participation, both in activities of daily living (ADL) and in the ambit of community integration, including social relationships and productivity (Whiteneck et al., 1992; Brown et al., 2004; Gordon et al., 2006; McCabe et al., 2007), is considered the ultimate goal of ABI rehabilitation. However, as pointed out by Goranson et al. (2003), non-comparability of outcome measures makes it difficult to evaluate evidence of rehabilitation efficacy. In fact, reported results of cognitive rehabilitation concern multiple domains of functioning and/or have been obtained using many different methods of measurement. A specific problem is that many studies evaluate treatment effectiveness by means of tools assessing gains in cognitive functions, but fail to show how these gains generalize to everyday situations (Cicerone et al., 2000).
Moreover, the improvements sought through a multidisciplinary rehabilitation program need to be defined in terms of recovery of autonomies in different domains relative to ADL, such as home management and extra-domestic activities, and in social relationships and productivity (Ponsford, 1995; Wilson, 2003). Consequently, there has emerged a need to examine multiple areas of functioning through assessment of different domains, in order to allow healthcare professionals to identify and implement concrete and specific rehabilitation plans (Ponsford, 1995; Wilson, 2003).
In rehabilitation, independence and autonomy are two different concepts (Tamaru et al., 2007). Independence is the ability to act in accordance with one's wishes and to perform activities without help from others (i.e. self-reliance); autonomy, on the other hand, is defined as self-determination and the ability to make decisions (Sève-Ferrieu, 2009). To be considered autonomous, an individual must be able to decide about his/her life and to start and complete everyday activities, finding appropriate solutions to any problems encountered. Being autonomous does not mean doing something unaided, and autonomy is not a peculiarity of individuals with full cognitive abilities. All those who depend on others, due to cognitive disability or to any other form of disability, can aspire to a level of autonomy compatible with their person. Autonomy, which includes motivation, the capacity to identify one's own needs and goals, and to formulate plans together with the drive to pursue them, can be defined as the ability to plan one's own life, relate to others, and participate with others in the construction of society (Andrich and Porqueddu, 1990). This definition can be translated into an "equation": autonomy = relationship, understood on three levels: relationship with oneself, with others, and with the environment. This is why the concept of autonomy is relevant to everyone, and it is also why a severely disabled individual who is dependent on others can nevertheless be considered autonomous, if he/she has struck a balance on all these three levels. The onset of a disability brings about a change in the life of an individual and requires him to construct a new relationship with himself, with others and with the environment in order to recover his autonomy. Autonomy is fundamental to client-centered rehabilitation since it is a prerequisite for effective participation in one's own life (Russell et al., 2002; Cardol et al., 2002).

Independence, on the other hand, is associated with an individual's level of physical functioning and ability to perform ADL unaided (Davies, et al., 1997). In other words, independence must be viewed as a contributing factor to personal autonomy. However, there are certain other factors that have a far greater influence on decision-making autonomy than physical conditions, for example memory dysfunctions or dysexecutive symptoms. It often occurs that patients considered independent actually need to be prompted to perform activities (Bottari et al., 2009). Moreover, autonomy is dependent on different situations and cultural backgrounds and therefore not a fixed or static concept (Tamaru et al., 2007).

By way of a conclusion to this brief, and hardly exhaustive, introduction to this topic, it should be emphasized that a person's autonomy should not be reduced only to his/her neuropsychological abilities (Sève-Ferrieu, 2009). On the contrary, it is necessary to take into account the influence of the material, human and social environment, applying a correct "biopsychosocial" approach to the individual, in line with that adopted by the International Classification of Functioning, Disease and Health (ICF) (OMS, 2001).

For the purpose of obtaining a comprehensive profile of an individual's autonomy over different domains, the existing measurement and monitoring tools seem rather poor. In fact, although several scales assessing functional autonomies are available in the literature, they focus mainly on personal independence correlated above all with motor functions and do not exhaustively assess other domains. Most of them do not analyze a broad profile of autonomies or consider their progression during the cognitive and behavioral rehabilitation process. In addition, most scales used in the evaluation of independence/autonomy take into consideration a specific function and are therefore of limited application in subjects with severe ABI, whose residual impairment requires broad and detailed characterization before, during and at the end of rehabilitation (Bottari et al., 2009). Some scales focus on ADL measurements, e.g. the Barthel Index (BI) (Mahoney and Barthel, 1965), the ADL Index (Katz et al., 1963), and the Functional Independence Measure (FIM) (Keith et al., 1987), while others highlight levels of independence and integration in the domestic, social and work spheres, i.e. the Frenchay Activities Index (Holbrook and Skilbeck, 1983), the ERTOMIS Assessment Method (Schian and Kronauer, 1991), the Craig Handicap Assessment and Reporting Technique (Whiteneck et al., 1992), the Community Integration Questionnaire (CIQ) (Willer et al., 1993), the Nottingham Extended ADL Scale (Nouri and Lincoln, 1987), and the Independent Living Scale (ILS) (Ashley et al., 2001). Moreover, in order to define disabilities and monitor improvements, it has been shown to be necessary to design individual rehabilitation programs as well as quantify individual rehabilitation effects.

Finally, since ABI rehabilitation is effective when the patient has and continues to have a close relationship with his/her family, it is necessary to assess more precisely the patient's degree of autonomy as perceived both by the patient and his/her caregiver. It is also necessary to assess both the patient's and the caregiver's awareness of the changes and possible improvements due to the rehabilitation intervention (Mazaux et al., 2004).

In view of the above considerations, we created a new tool to be used to define broad disability profiles in ABI patients submitted to rehabilitation for cognitive-behavioral disturbances. The instrument, called the Progression of Autonomies Scale (PAS), measures levels of autonomy in ADL, in domestic activities, and in the external environment. The instrument was also created with a view to supporting the design of individual rehabilitation plans targeting enhancement of autonomy.

Materials and methods

Scale design

The PAS was designed to evaluate the consequences of disability in terms of levels of autonomy in different domains, and also to evaluate the progression of recovery and the efficacy of the rehabilitation intervention over a wide range of activities, requiring progressively more complex integration of cognitive and behavioral functions. The PAS is structured in such a way as to characterize the subject's autonomy and its progression over time, and it is organized in three macrodomains: 1- Personal, 2- Domestic and 3- Extra-domestic. This structure reflects the experience of the Cognitive and Behavioral Integrated Rehabilitation Unit at the S. Anna Institute and the approach it adopts in its daily practice, i.e. consideration of the progression of the individual's autonomy in different domains. What this means in practical terms is that in the context of an individually designed rehabilitation program, an ABI patient will, for example, be included in extra-domestic rehabilitation activities only when he/she demonstrates sufficient autonomy in personal and domestic activities (scores ≥2 on ≥75% of items in the respective domains).

Obviously, some of the PAS items are already present in other scales commonly used for the evaluation of ADL in the rehabilitation setting, for example items concerning self-care activities or cooking, but our scale includes more items in order to define a more exhaustive disability profile.

The PAS in its present structure was obtained by reducing and re-organizing the eighty-two items of the original scale (Crotone Progression of Autonomies Scale, "SPAK" Table I) and by eliminating items identified through a statistical procedure. The final version of the PAS is shown in table II (over).

Scale administration

The scale is administered twice by an occupational therapist during a direct observation period: before the inpatient begins a cognitive-behavioral rehabilitation treatment, and at its end. In both of these assessments, the occupational therapist observes the subject performing the activities required by the PAS items and assigns a score (objective score), according to the criteria described below. The same scale is also administered as a questionnaire to both the patient and his/her caregiver on the patient's admission, in order to verify their degree of awareness of the patient's present disabilities, and again at the end of the rehabilitation program to define the improvements obtained and possible increases in the degree of patient and caregiver awareness.

Comparing the three different scores assigned to each

Table I - The original 82-item Crotone Progression of Autonomies Scale (SPAK)

Personal autonomy	Domestic autonomy	Extra-domestic autonomy	Social/Working autonomy
1. Washing one's hands	29. Picking up a pen and writing	60. Going somewhere on foot alone	74. Organizing meetings with family and friends
2. Washing one's face	30. Cutting with scissors/a cutter	61. Crossing the road	75. Going to the cinema/ theater/ stadium/other
3. Using the W.C.	31. Inserting key in the lock and turning it	62. Consulting public transport timetables	76. Planning holidays
4. Using a bidet	32. Screwing and unscrewing	63. Using public transport	77. Doing hobbies
5. Taking a bath/shower	33. Finding a telephone number in the telephone directory/ phone book	64. Consulting a map	78. Taking on responsibility for the care of others
6. Washing one's hair	34. Using telephone/mobile/ house phone	65. Road safety	79. Doing one's own work/studies
7. Drying one's hair (with hair-dryer/towel)	35. Using the remote control and watching TV	66. Recognizing cash	80. Carrying out new work/ Beginning new studies
8. Combing one's hair	36. Asking for help if in need	67. Estimating the value of things	81. Continuing one's course of studies/career
9. Brushing one's teeth	37. Avoiding dangerous substances	68. Doing shopping for the home	82. Respecting times, deadlines, etc.
10. Shaving/making up	38. Managing dangerous activities	69. Making personal purchases	_____
11. Caring for/cutting fingernails	39. Managing pharmacological therapy	70. Spending in proportion to own resources	_____
12. Caring for/cutting toenails	40. Opening and closing windows	71. Managing a bank current account	_____
13. Putting on underwear	41. Preparing a hot drink	72. Using a credit card	_____
14. Changing underwear regularly	42. Preparing a cold meal	73. Making payments in public offices	_____
15. Putting on a T-shirt/ sweater	43. Preparing a hot meal	_____	_____
16. Putting on shirt/blouse	44. Using small domestic electrical appliances	_____	_____
17. Putting on (and buttoning up) trousers/slacks or skirt	45. Using kitchen utensils appropriately	_____	_____
18. Putting on socks/tights	46. Laying the table	_____	_____
19. Putting on and taking off shoes	47. Clearing the table	_____	_____
20. Putting on accessories (belt, gloves)	48. Washing the dishes	_____	_____
21. Sitting down correctly to eat	49. Using white domestic appliances	_____	_____
22. Using cutlery correctly	50. Sweeping	_____	_____
23. Corking and uncorking a bottle	51. Cleaning the floor	_____	_____
24. Pouring a drink	52. Dusting	_____	_____
25. Drinking from a glass/cup	53. Making the bed	_____	_____
26. Breaking bread	54. Tidying up bathroom/ bedroom/kitchen	_____	_____
27. Wiping mouth	55. Doing the washing	_____	_____
28. Respecting meal times and displaying appropriate eating/table behaviors	56. Hanging out the washing	_____	_____
_____	57. Ironing	_____	_____
_____	58. Making a shopping list	_____	_____
_____	59. Respecting due dates of bills	_____	_____

Table II - (A) Final version of the Progression of Autonomies Scale with three domains (English version)

Personal autonomy	Domestic autonomy	Extra-domestic autonomy
1. Washing hands and face	16. Inserting a key into a lock and turning it	29. Crossing the road
2. Using the toilet	17. Using telephone/mobile	30. Using public transport
3. Taking a bath/shower	18. Managing hazardous activities	31. Recognizing cash
4. Combing hair	19. Managing pharmacological therapy	32. Estimating the value of things
5. Brushing teeth	20. Opening and closing windows	33. Doing the shopping
6. Shaving /putting on make-up	21. Preparing a hot meal	34. Spending in proportion to own resources
7. Regularly changing underwear	22. Laying the table	35. Organizing meetings with family and friends
8. Putting on a vest top/shirt/sweater	23. Clearing the table	36. Going to the cinema/theater/ stadium/other
9. Putting on and fastening trousers/skirts	24. Using household appliances	37. Taking on responsibility for the care of others
10. Putting on and taking off shoes	25. Tidying up bathroom/ bedroom/kitchen	38. Respecting times/deadlines, etc.
11. Using cutlery correctly	26. Ironing	
12. Pouring drinks	27. Making a shopping list	
13. Breaking bread	28. Respecting due dates of bills	
14. Wiping mouth		
15. Respecting meal times and displaying appropriate eating/table behaviors		

Table II - (B) Final version of the Progression of Autonomies Scale with three domains (Italian version)

Autonomia personale	Autonomia domiciliare	Autonomia extra-domiciliare
1. Lavarsi le mani ed il viso	16. Introdurre una chiave in una serratura e girarla	29. Attraversare la strada
2. Usare il WC	17. Usare telefono/cellulare	30. Usare i mezzi di trasporto pubblici
3. Fare il bagno/doccia	18. Gestire attività pericolose	31. Riconoscere il denaro contante
4. Pettinare i capelli	19. Gestire terapia farmacologica	32. Stima del valore delle cose
5. Lavarsi i denti	20. Aprire e chiudere finestre	33. Fare la spesa di casa
6. Farsi la barba/truccarsi	21. Preparare un pasto caldo	34. Spendere in maniera proporzionata alle proprie risorse
7. Cambiare regolarmente la biancheria intima	22. Apparecchiare la tavola	35. Organizzare incontri con familiari e amici
8. Indossare una canottiera/maglietta/ maglione	23. Sparecchiare la tavola	36. Andare al cinema/teatro/stadio/ altro
9. Indossare e allacciare pantaloni/gonna	24. Usare gli elettrodomestici	37. Assumersi responsabilità nella cura di altri
10. Calzare e togliere le scarpe	25. Riordinare bagno/camera/ soggiorno/cucina	38. Rispettare orari/scadenze
11. Usare appropriatamente le posate	26. Stirare	
12. Versarsi da bere	27. Fare la lista della spesa	
13. Spezzare il pane	28. Rispettare la data di scadenza delle bollette	
14. Pulirsi la bocca		
15. Rispettare tempi e modi nell'alimentazione		

item (by the patient, the caregiver, and the occupational therapist), it is possible to highlight how the single patient, and caregiver, perceives the disability. In particular, the aim is to quantify how similar the patient and caregiver's evaluations are to the occupational therapist's objective assessment, with regard to i) the patient's basic functioning and autonomy before starting rehabilitation treatment, and ii) the level of recovery at discharge.
The degree of mismatch detected can provide indications for planning the patient's rehabilitation treatment, as well as for optimizing the training and involvement of the caregiver. The caregiver is indeed required to provide a certain degree of assistance during the recovery process, stimulating the patient in his/her recovery of autonomy. This is true even when the patient seems to be less responsive to treatment, for example in cases of cognitive deficits secondary to the injury (such as global amnesia) or frontal lobe injury.
Finally, one of the general goals of the rehabilitation team should be to reduce, as far as possible, the mismatch between the evaluations of the caregiver, patient and healthcare professionals.
A bar plot embedded in the PAS Excel sheet was used to compare the patient and caregiver's subjective awareness of the patient's disability(ies) with the objective assessment provided by the occupational therapist (Fig. 1).

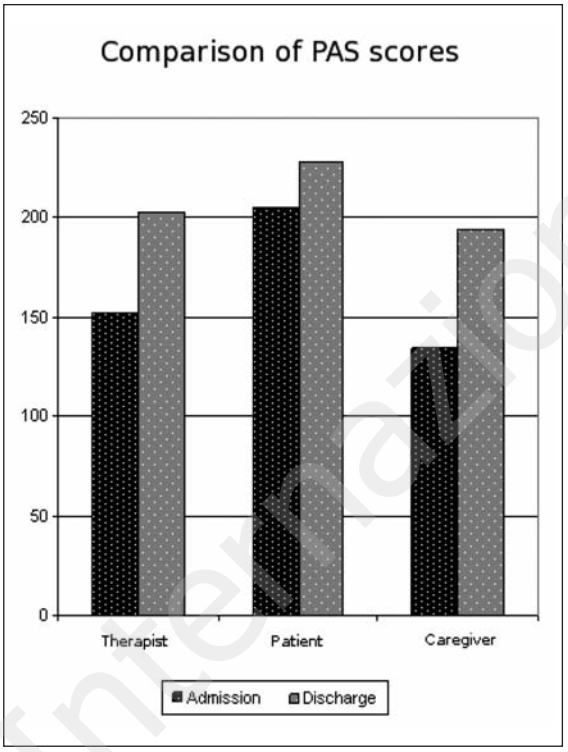

Figure 1 - PAS global scores, on admission and at discharge, as assigned by the therapist, patient and caregiver.

Score attribution

The therapist assigns each item a score ranging from 0 to 3 (Table III), where 3 indicates full autonomy and 0 indicates complete lack of autonomy. Items are scored using a four-level ordinal scale, from zero to three: 0 = activity not observed, not executed, never executed before injury, never executed after injury, refusal to perform the activity, full dependence; 1 = activity executed through physical contact or verbal suggestion, partial dependence; 2 = activity executed through a compensation strategy, assistance, environmental adaptation, and requiring a longer time, partial autonomy; 3 = activity carried out in complete autonomy, as before the injury, full autonomy. The discriminating factor is the difference between scores 0, 1 (caregiver required) and 2, 3 (caregiver not required) (Table III).
When assigning scores the occupational therapist can also take into consideration staff members' observations, as reported, for example during meetings of the rehabilitation team, although these must be followed by direct verification.

The multicenter study

As already mentioned, the original scale (SPAK) was reduced and reorganized on the basis of data collected during a prospective, multicenter study of inpatients recruited, according to the inclusion criteria detailed below, from the following rehabilitation centers:
• RAN (Research in Advanced Neurorehabilitation), S. Anna Institute, Crotone
• Salvatore Maugeri Foundation, IRCCS, Scientific Institute of Montescano
• S. Maria ai Servi, Don Gnocchi Foundation, Parma

Table III - System for scoring of items by the therapist

Score	Description	Caregiver required in order to complete the action
0	Activity not observed, not executed, never executed before injury, never executed since injury, refusal to perform activity, patient totally dependent	*Caregiver required*
1	Activity supported by physical contact or verbal suggestion, patient partially dependent	*Caregiver required*
2	Activity executed with compensation strategy, assistance, environmental adaptation, requiring a longer time, patient partially autonomous	*Caregiver not required*
3	Activity carried out in complete autonomy, as before the injury, patient totally autonomous	*Caregiver not required*

• Rehabilitation Pole of East Liguria, Don Gnocchi Foundation, Sarzana (SV)
• Cognitive Neuroscience Study and Research Center, Cesena
• S. Stefano Rehabilitation Center, Porto Potenza Picena (MC).
The study protocol was approved by the ethics committee of the S. Anna Institute. Prior to the evaluation, the patients and, in some cases, the caregivers as their legal guardians were given verbal and written information on the study and signed an informed consent form upon admission to the trial.
The *inclusion criteria* were: inpatient aged 16-65 years, of either gender, with severe ABI (Glasgow Coma Scale score ≤8; coma duration more than 3 days) of any etiology (traumatic, hemorrhagic, anoxic, infectious), evaluated at any time from injury (during the advanced phase of post-acute rehabilitation, or after an unsuccessful attempt at social reintegration); the *exclusion criteria* were: motor, cognitive or behavioral disabilities prior to ABI, degenerative brain disease, age under 16 or over 65 years.
The following *parameters* were considered: gender, age, education, handedness, time from brain injury, length of stay, and motor, cognitive or behavioral disabilities. The PAS was administered both on admission and at discharge. For comparison and cross-validation, the FIM (Keith et al., 1987) was administered on admission and at discharge to all admitted patients and the CIQ (Willer et al., 1993; Lombardi et al., 1997) was administered three months after discharge.

Statistical analysis

Scale reduction was performed first by identifying redundant items through a hierarchical clustering procedure (Everitt, 1974). For each domain, items with a Spearman correlation (Spearman, 1904) greater than 0.8 were grouped together, and only a subset of items was retained per group. Items to be kept were chosen by the clinical researchers on the basis of qualitative considerations, e.g. ease of administration, usefulness for clinical purpose, etc.
After the elimination of the redundant items, Rasch analysis (Andrich, 1988) was applied to the remaining 47 items in order to identify those violating the assumptions of the item response theory (IRT) (Hambleton et al., 1991). The IRT provides a set of mathematical models able to detect abnormalities in the structure of measurement scales. For this purpose, the IRT attributes an ability score to each subject (usually referred to as "person location") and a difficulty score to each item ("item location"). Skilful subjects are expected to obtain high scores for most of the items, while impaired subjects should fail even the easiest ones. When the results of the test do not reflect these assumptions, it is legitimate to suspect that global test scores are distorted (i.e. global scores are affected by factors external to the trait under analysis). The reduced scale was analyzed iteratively using a Rasch partial credit model (Masters, 1982); at each iteration, misfitting items (p value <0.05) were considered for elimination.
The final decision on item elimination was left to the panel of researchers and experts who devised the original scale. Once the reduced, final version of the scale had been obtained, patients' individual data were tested to perform a preliminary evaluation of its validity and internal consistency reliability. We employed the same set of data for both scale reduction and scale validation, thus the results of the latter are clearly biased. Nevertheless, we decided to perform a preliminary evaluation of the validity of the scale in order to provide a first insight into the correctness of the PAS structure.
Content validity (i.e. the correctness of the structure of the scale, divided into domains) was estimated by identifying highly correlated scores and clusters in a covariance matrix of the items and by defining the extent of matching between significant clusters and the scale structure (exploratory factor analysis, EFA) (Gorsuch, 1983). The number of factors to be considered in the analysis was determined through the visual "scree test" (Cattel, 1966) performed on the eigenvalue weights.
The internal consistency reliability is a measure of the consistency between items belonging to the same domain and it was assessed by separately computing the Cronbach's alpha statistics (Cronbach, 1951) for each PAS domain on admission and at discharge.
Convergent validity (i.e. the degree of correlation between theoretically similar measures) was estimated by comparing the PAS score with both the FIM and the CIQ scores. In particular, Spearman's correlation indices were calculated between PAS and FIM scores on admission and between PAS and CIQ scores at discharge (Fig. 2). In addition, floor and ceiling effects were investigated by analyzing the percentages of extreme scores. All the analyses were conducted with the R statistical software (www.r-project.org).

Results

Study sample

One hundred and twenty seven consecutive inpatients (16-65 yrs; mean: 36.6±13.7 yrs) with severe ABI (traumatic: 72.0%; anoxic: 16.1%; hemorrhagic: 8.5%; infectious: 3.4%) were recruited from March 2007 to January 2009. The majority were males (74%), but the males: females ratio was consistent with the gender prevalence of brain injuries (Kraus, 1993; Sorensen and Kraus, 1991). Sample descriptive statistics are reported in tables IV and V. All the 127 inpatients selected for the study completed the observational period and the rehabilitation program, allowing the occupational therapists to score the autonomy profile on admission and at discharge.

Scale reduction

The hierarchical clustering of items belonging to the original SPAK scale identified respectively 8, 14, 8 and 8 groups for the Personal, Domestic, Extra-Domestic and Social-Working domains. The clinical researchers decided to retain 15, 16, 8 and 8 items from each domain.
Iterative application of the Rasch partial credit model identified nine additional items to be eliminated. Almost all the items of the Social/Working domain were considered misfitting and eliminated, except for the items: Going to the cinema/theater/stadium/other; Taking responsibility for the care of others; Respecting times, deadlines, etc. This is in partial contrast with our previous

findings, where we claimed that the fourth domain of SPAK was in agreement with IRT assumptions. The previous findings were obtained by applying the Rasch model to each PAS domain in isolation, whereas the results presented in this paper are based on analysis of the whole scale. Thus, these results indicate that inclusion of the Social/Working domain in the PAS scale would give a global score that goes against the IRT assumptions. Consequently, we decided to remove the Social/Working domain from the scale and to assign its three retained items to the other domains. Table IIa shows the final three-domain version of the PAS.

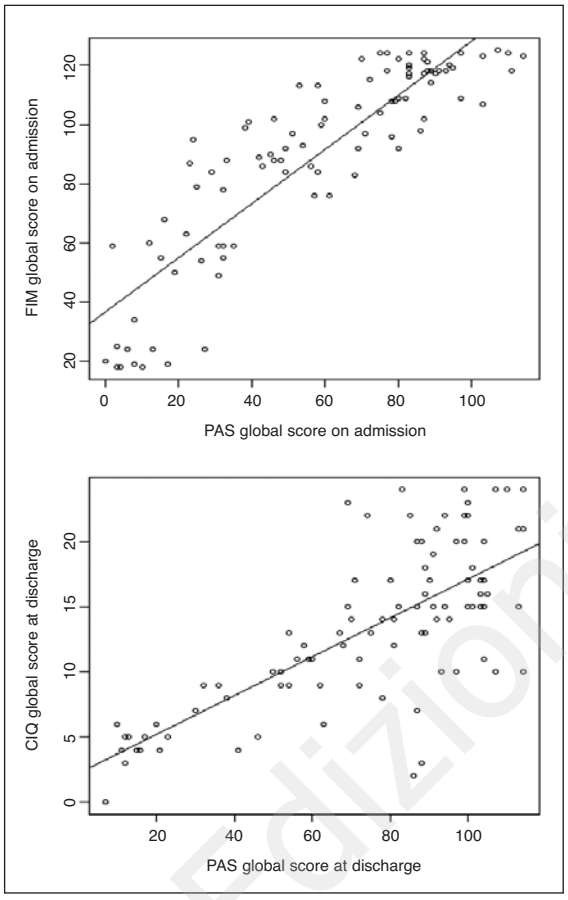

Figure 2 - PAS global scores versus Functional Independence Measure global scores on admission and at discharge.

Table IV - Demographics of the patients admitted to the multicenter prospective study

Demographic variables	
Age (yrs)	36.6±13.7 yrs
Time from brain injury (days)	1119.8±2067.7
Time in hospital (days)	79.3±59.0
Right-handed	117 (92.1%)
Presence of motor disabilities	73 (57.5%)
Presence of behavioral disabilities	64 (50.4%)
Presence of cognitive disabilities	117 (92.1%)

Whole sample: n=127. Where appropriate, values are indicated as mean ± SD.

Validation

Figure 3 (over) shows the eigenvalue plots deriving from the EFA, one for each domain of the scale and one for the global score, with separate lines for admission and discharge. The slopes of the lines flatten out after the first eigenvalue, meaning that each of the three PAS domains was adequately described by one factor, both on admission and at discharge. In particular, the first eigenvalue explains more than 60% of the variance for each domain. Adding the adjacent factors (e.g. second and/or third) did not significantly increase the explained portion of the total (Fig. 3).

For each PAS domain at admission and at discharge, as well as for the whole scale, Cronbach alpha values were above 0.9, indicative of a good internal consistency [the generally accepted significance cut-off is 0.7 (Streiner and Norman, 1989)].

The PAS and FIM global scores showed high correlation indices both on admission and at discharge, respectively p=0.88 and p=0.83. Interestingly, the first 13 items of the FIM correlated strongly with the PAS first domain scores (p=0.89 on admission and p=0.85 at discharge) but less strongly with the PAS third domain scores (p=0.72 on admission and p=0.65 at discharge). Conversely, the last five items of the FIM were more in agreement with the third domain of the PAS (p=0.85 and p=0.84) than with the first domain (p=0.76 and p=0.70). Spearman correlation indices also showed good concordance between PAS and CIQ scores (p=0.70).

The percentages of patients recording extreme scores (i.e. maximum or minimum achievable scores) were calculated both for the single domains and the whole scale. No ceiling or floor effects were detected for the PAS global scores: the percentage of subjects recording the maximum score was less than 4% both at admission and discharge, as was the percentage of subjects with the minimum score. A slight ceiling effect was found for the Personal Autonomy domain scores at admission and discharge (18.9% and 23.5% of subjects recorded the maximum score, respectively).

Discussion

Most outcome scales used in rehabilitation evaluate activity or independence profiles based on specific dysfunctions. Therefore, they have limited applicability in subjects with severe ABI, whose residual impairments

Table V - Average PAS scores, on admission and at discharge. Values are indicated as mean±SD.

PAS scores	admission	discharge
PAS global score	59.3±33.8	70.3±34.2
Personal autonomy	29.6±13.9	33.4±13.5
Domestic autonomy	16.2±12.3	20.1±12.6
Extra-domestic autonomy	13.5±9.5	16.9±9.8

are complex, interlinked and mostly represented by cognitive and behavioral deficits, which need to be defined in detail before and during rehabilitation processes (Giles, 2010; Kim and Colantonio, 2010). As specified in the introduction, there are many instruments for the targeted assessment of ADL, e.g. the BI (Mahoney and Barthel, 1965), the Index of ADL (Katz et al., 1963), and the FIM (Keith et al., 1987). There also exist many scales that focus on a subject's functioning in terms of their level of participation in domestic and social spheres, e.g. the Frenchay Activities Index (Holbrook and Skilbeck, 1983), ERTOMIS Assessment Method (Schian and Kronauer, 1991), the Craig Handicap Assessment and Reporting Technique (Whiteneck et al., 1992), the CIQ (Willer et al., 1993; Lombardi et al., 1997), the Nottingham Extended ADL Scale (Nouri and Lincoln, 1987), and the ILS (Ashley et al., 2001). However, to our knowledge, no evaluation scales are available which investigate an ABI patient's autonomy profile in terms of his/her self-determination and ability to make effective decisions in different domains: personal, domestic, and extra-domestic. Since ensuring that the patient achieves the best possible level of participation in real life is unanimously considered the ultimate goal of rehabilitation (Ponsford, 1995, 2004; Wilson, 2003; Marcotte and Grant, 2010), we deemed it necessary to create an additional evaluation scale assessing autonomies in the above indicated domains.

The PAS provides not only functional assessment of autonomies in several domains at the same time, but also a means of monitoring the patient's progress during rehabilitation. Furthermore, a PAS-based functional assessment is the result of patient observation performed by an occupational therapist during activities performed in a rehabilitation setting (those related to personal autonomy, domestic activities and some social activities) and outside the home. Finally, the PAS can be used as a questionnaire to be administered, separately, to patient and his/her caregiver with the aim of comparing the patient's dysfunctional profile (assessed by occupational therapist) with the patient and caregiver's subjective perception both of the patient's basic functioning and of his/her rehabilitation progress.

This observational assessment, performed on admission and at the end of the rehabilitation period, makes it possible identify the domains in which the patient succeeds or does not improve (achieves or does not achieve autonomy). As a consequence, the PAS could also contribute to the tailoring of a further and more focused goal-directed rehabilitation program (Cicerone et al., 2004).

Similarly, repetition of the questionnaire assessment at discharge is aimed at evaluating changes in the initial gap between the therapist's observations and the level of patient and caregiver awareness (Fig. 1). A reduction of

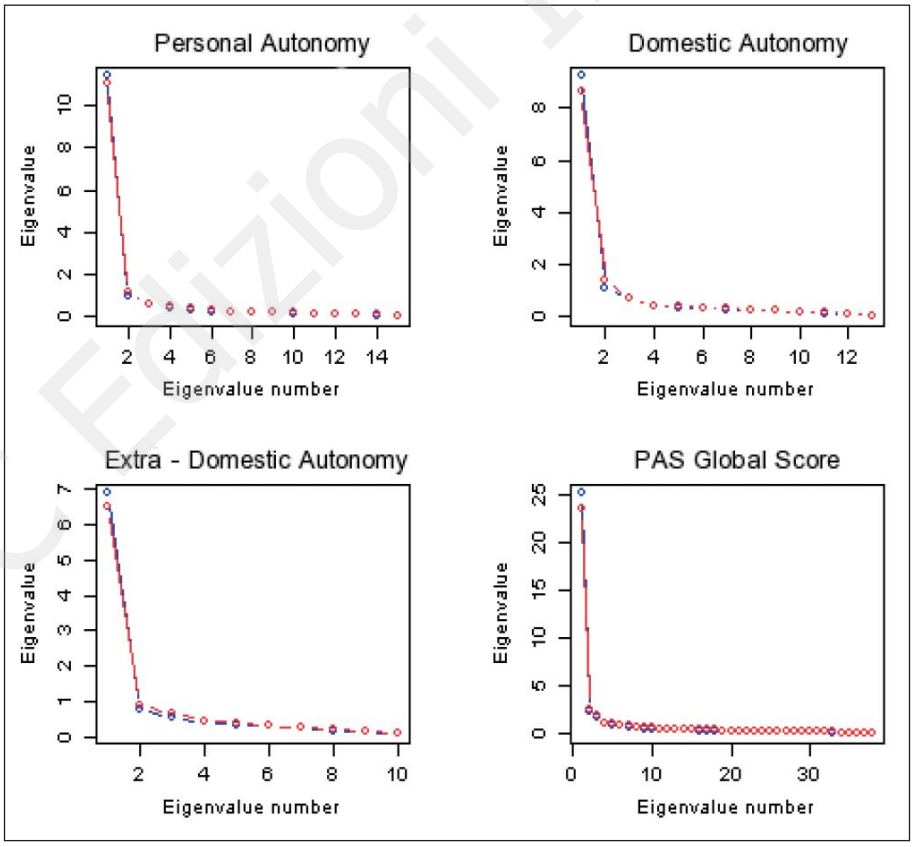

Figure 3 - Eigenvalue plots for PAS single domain and global scores.
The red lines refer to admission, and the blue ones to discharge. Both on admission and at discharge, and both for PAS global score and subdomain scores, the first eigenvalue is considerably higher than the remaining ones, suggesting the presence of a unique latent factor in all cases.

this gap, which corresponds to an increased awareness on the part of the patient/caregiver, would constitute a guarantee of maintenance of the rehabilitation effects over follow-up (Mazaux et al., 2004; Prigatano, 1999).
Spearman's correlations highlighted a good concordance between FIM and PAS first domain scores, and between CIQ and PAS third domain scores (Fig. 4). The high levels of agreement between PAS, CIQ, and FIM were not unexpected since the constructs measured by the CIQ and the FIM are related to the autonomies measured by the PAS. However, as we pointed out above, the distinctive feature of the PAS is that it provides a progressive assessment of the autonomies of the subject, from the Personal to the Extra-Domestic domains. The other two scales (FIM and CIQ), both commonly applied in rehabilitation settings, focus on narrower aspects of patient recovery, considering only functional aspects (FIM) or, at the other extreme, the complex construct of community integration (CIQ).
The internal reliability estimates indicate that the scoring is not affected by the limited range of scores that can be assigned to each item (from 0 to 3); furthermore, this range reduces risk of ranking errors and a resulting random distribution of scores. The reduction of ranking errors could also be explained by the strictness of the score assignment criteria.
Finally, the analysis of the score distributions revealed a small ceiling effect in the Personal Autonomy domain scores: our results show that about 19% of the subjects were able to reach a perfect score in the Personal Autonomy domain on admission. This percentage may seem quite high, especially considering the severity of the patients' ABI. However, we can read the same datum the other way round, i.e., 80% of ABI patients are not able to perform the most basic daily actions. From this point of view, the results seem to be in line with common clinical experience (Turner-Stokes et al., 2005).
In conclusion, the PAS, based on definition and management of autonomies, could well be a helpful assessment tool in the setting of cognitive and behavioral rehabilitation after ABI.
However, it is proper to highlight some limitations of the present study. First, we still lack a third, independent sample in which to perform a definitive validation of the PAS. We are currently designing a wider multicenter study to collect the necessary data. In the course of the forthcoming study, we also plan to better characterize the reliability of the scale, particularly with regard to inter and intra-rater reliability. Second, even though the aim, in designing the PAS, was to create a general tool to be applied in various healthcare settings, to date it has been administered only to ABI subjects. Thus, our results should be considered valid only under comparable conditions. Finally, further analysis should be performed in order to better investigate the relationships between score profiles as defined by staff members' direct observation and score profiles as defined by the questionnaire submitted to both patients and caregivers.

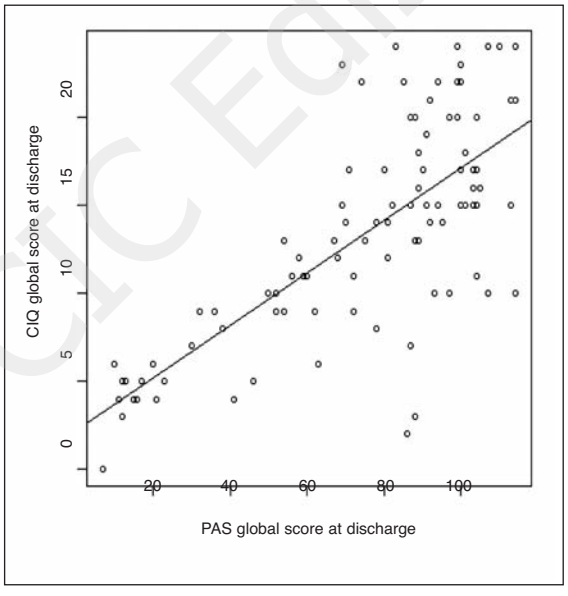

Figure 4 - PAS global scores versus Community Integration Questionnaire global scores at discharge.

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