Content comparison: quality of life and functioning scales in non-traumatic spastic paraparesis according to the International Classification of Functioning, Disability, and Health

Comparação do conteúdo entre: qualidade de vida e escalas de funcionalidade para a paraparesia espástica não-traumática de acordo com a Classificação Internacional de Funcionalidade, Incapacidade e Saúde

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ABSTRACT
Objective: Identify instruments used for the functional evaluation of people with Non-traumatic Spinal Cord Injury (NTSP), and compare their contents according to ICF concepts. Method: Literature review was conducted in the Medline, Scielo, Pubmed, and Bireme databases with the descriptors “spastic paraparesis,” “functional evaluation,” “neurological examination,” “neurological scales,” “neurological evaluation,” and “neurological evaluation measurements,” to find articles reporting the functional evaluation scales having been applied on individuals with NTSP. The content of such instruments was compared after linking them to ICF. Results: The systematic review identified 12 instruments for functional evaluation instruments of NTSP, in we described 153 ICF categories, concentrated mainly in: neuromusculoskeletal functions, digestive, motor activities, and self-care. Among the environmental factors: assistive technology for mobility, to pe...rsonal use in daily life deserved greater attention. Conclusion: This study provided a guide to identify instruments to evaluate the functionality of individuals with NTSP.

Keywords: International Classification of Functioning, Disability and Health, Spinal Cord Injuries, Paraparesis, Spastic, Surveys and Questionnaires, Quality of Life

RESUMO
Objetivo: Identificar instrumentos utilizados para a avaliação funcional de pessoas com lesão medular não-traumática (LMNT) e comparar seu conteúdo de acordo com os conceitos da CIF. Método: A revisão sistemática foi realizada nas bases de dados Medline, Scielo, Pubmed e Bireme com os descritores “paraparesia espástica”, “avaliação funcional”, “exame neurológico”, “escalas neurológicas”, “avaliação neurológica” e “medidas de avaliação neurológica”. Para encontrar artigos relatando as escalas de avaliação funcional aplicadas em indivíduos com LMNT. O conteúdo de tais instrumentos foi comparado após vinculá-los à CIF. Resultados: A revisão sistemática identificou 12 instrumentos de avaliação funcional de LMNT, foram identificadas 153 descrições das categorias da CIF, concentradas principalmente em: funções neuromusculoesqueléticas, digestivas, atividades motoras e autocuidado. Entre os fatores ambientais: a tecnologia assistiva para mobilidade, para uso pessoal na vida cotidiana, mereceu maior atenção. Conclusão: Este estudo forneciu um guia para identificar instrumentos para avaliar a funcionalidade de indivíduos com LMNT.

Palavras-chave: Classificação Internacional de Funcionalidade, Incapacidade e Saúde, Traumatismos da Medula Espinal, Paraparesia Espástica, Inquéritos e Questionários, Qualidade de Vida
INTRODUCTION

Non-traumatic spinal cord injuries include a group of varied etiology in which the most exuberant clinical sign is the spastic paraparesis, predominantly of lower limbs with insidious beginning, slow progression, associated with varied degrees of sensory and sphincter impairment.6,23

It can occur due to some diseases such as hemorrhages, tumors, viral infections, and vascular and degenerative alterations, as well as spinal malformations, secondary vertebral subluxations, rheumatoid arthritis, or degenerative joint disease.4,5,6

In addition to giving attention to the deficiencies of physiological functions, the rehabilitation intervention requires the observation of the individual’s performance in meaningful tasks in his life experience, according to the environment in which he or she lives. Thus, a comprehensive evaluation presupposes the observation of all of these aspects. In the specific case of non-traumatic paraparesis, the most frequently recommended functional evaluations are the Osame Motor Disability Scale (OMDS)7 and the Functional Independence Measure (FIM).8

The ICF was published by the WHO in 2001 to describe the functioning and relevant contextual factors in the life experiences of people. It reformulates concepts unifying the medical and social models in the understanding of disability and it can be used to obtain an interaction of various health dimensions such as the individual, social, and biological.9

In order to render its practical and routine use viable, ICF-based instruments have been developed for clinical use10 and for public policies.11 By supplying a universal and standardized language, it can be used as a tool to compare functional evaluation instruments, since the concepts present in these instruments can be translated into a common language.12

Clinical manifestations of traumatic and non-traumatic spinal cord injuries are very similar, in order to identify more specific aspects of functioning we conducted a literature review based on functional assessment measures for spastic paraparesis of non-traumatic etiology.

OBJECTIVE

The objective of this study was to list the instruments used in the functional evaluation of individuals with non-traumatic paraparesis in the scientific literature and to compare their contents using the ICF as a reference standard. We prioritized the use of the validation articles in the study original language.

METHODS

A systematic literature review was performed in the Medline, Scielo, Pubmed, and Bireme databases in all languages, to find articles that examined non-traumatic spastic paraparesis, in which the functional evaluation scales had been applied. The bibliographical survey was made in January of 2020. Case reports, patients series, observational, interventional, and psychometric studies were selected, in addition to reviews.

Identification of the functional evaluation measurements in non-traumatic spastic paraparesis and their link with the ICF

The keywords used in this search were: ‘spastic paraparesis’, ‘transverse myelitis’, ‘non-traumatic spinal cord injury’, ‘functional evaluation’, ‘paraparesis’, ‘neurological evaluation’, ‘neurological evaluation measurements’, ‘questionnaires’, ‘functioning’, and ‘quality of life’. The articles that discussed non-traumatic spinal cord injury, regardless of etiology, diagnosed by neurological, image, or functional exams met the inclusion criteria.

All the study designs were considered, as long as they included the use of functional evaluation instruments.

Instruments that evaluated only one limited aspect of physiological functions such as only pain, diuresis, strength, or immunological aspects were not considered.

The instruments in question needed to include activities or participations that are understood by the ICF as the performance of tasks by an individual or his involvement in life situations.

The articles were analyzed initially by title and abstract to verify their pertinence to the syndromic clinical presentation of non-traumatic spastic paraparesis. After that, the articles were read to identify the functional evaluation instruments that were used. When the instruments could not be obtained directly from the articles, they were searched for in the bibliographical references.

Linking significant contents of the evaluation instruments to ICF followed the recommendations described by Cieza,13 categorizing them as a body function, anatomical structure, activity or participation or environmental factor.

Although not classified in ICF, the concepts were linked to personal factors or other concepts, like quality of life. We always sought out the category that best described the significant content present in the evaluation instrument, thus, there was no limitation regarding the level of classification in ICF.

Following the above recommendations, whenever an instrument’s significant content was identified as either “other, specified” or “not specified,” the category in the level immediately above was preferred over those which codes ended with 98 or 99, respectively.

In order to compare the instruments, spreadsheets were prepared to point out the occurrence of significant contents in each questionnaire. The frequency of occurrences of each ICF category was established based on the sum of the total number of times it was identified. A category was only considered once for each instrument.

RESULTS

The systematic review identified 12 functional evaluation instruments used for individuals with non-traumatic spastic paraparesis: Functional Independence Measure (FIM),4,14,15 Osame’s Motor Disability Scale (OMDS),16,17 Kurtzke Expanded Disability Status Scale (EDSS),17–21 Functional Assessment of MS (FAMS),22 Spinal cord Independence measure – 3 (SCIM-3),23,24 the Barthel ADL Index (BI),23,25,26 the SF-36 Brazilian Portuguese version,27 Spastic Paraplegia Rating Scale (SPRS),28 Functional Scale of hereditary Spastic Paraplegia (FSHSP),1 Gillette Functional Assessment Questionnaire (Gillette),29 Japanese Ohtopaedic Association (JOA),30 and Severity Score System for Progressive Myelopathy (SSPROM),17 from which only the OMDS, SCIM-3, SPRS, FSHSP, JOA, Gillette e SSPROM could be considered specific for non-traumatic spastic paraparesis.

Table 1 compares the overall contents of instruments. FIM was the instrument with the greatest number of ICF categories. It also shares 20.6% of its ICF categories with other instruments, and 13.5% of the categories are exclusive, guaranteeing a distinct role in the functional evaluation of individuals with non-traumatic spastic paraparesis.

Table 1. ICF categories of amount identified in each functional assessment tool for individuals with non-traumatic spastic paraparesis

| Abbreviation of rating scales | Total | ICF categories | Exclusive |
|------------------------------|-------|----------------|-----------|
| FIM                          | 51    | 38             | 13        |
| OMDS                         | 14    | 11             | 3         |
| EDSS                         | 21    | 17             | 4         |
| FAMS                         | 34    | 14             | 20        |
| SCIM-3                       | 29    | 26             | 3         |
| BI                           | 26    | 19             | 7         |
| SF-36                        | 30    | 16             | 14        |
| JOA                          | 18    | 8              | 10        |
| SPRS                         | 17    | 15             | 2         |
| FSHSP                        | 3     | 3              | 0         |
| GILLETTE                     | 13    | 12             | 1         |
| SSPROM                       | 34    | 22             | 12        |
On the other hand, easy to read and quick to apply instruments such as the OMDS and FSHSP stand out for presenting the lowest number of ICF categories, which shows their limitation for a more comprehensive evaluation.

The FAMS is the scale with the most exclusive categories, which are not seen in the other scales (11.6%) and there are a great number of personal factors such as “embarrassment in public places” or “feeling ill,” reflecting the concept of quality of life related to health — that is, the personal opinion of the individual about his own health experience (WHO-QL, 1998). In this instrument, 19 (55.8%) of the 34 significant contents identified could not be linked to the ICF categories, either because they referred to quality of life or to personal factors, or because they were not contained in the classification.13

Table 2 shows the occurrence of ICF categories of the Body Functions in each of these instruments. Fifty ICF categories were identified and represented six chapters. Pain sensation (b280), Urination functions (b620) and Urinary continence (b6202) were the most linked categories. However, when the categories were grouped under their respective chapters, the neuromusculoskeletal functions and those related to movement were mentioned in seven instruments; functions for mental in three, genitourinary and digestive system in six instruments; sensory functions in five, and cardiorespiratory in only one, and no instrument verified the functions of voice, speech, skin and related structures. Pain is evaluated in general, in the cephalic and cervical segment, or in joints by the FAMS, the SF-36, JOA and the SPRS, and only the SCIM-3 evaluated breathing. The FSHSP and Gilette scales scale did not evaluate any physiological function.

Table 2. ICF Component of the categories Body Functions in instruments used for functional assessment of patients with non-traumatic spastic paraparesis

| COMPONENT ICF | % | FIM | OMDS | EDSS | FAMS | SCIM-3 | BI | SF-36 | DAA | SPRS | FSH | GILLETTE | SSROM |
|---------------|---|-----|------|------|------|--------|----|-------|-----|------|-----|-----------|-------|
| b1263 - Psychic stability | 8,3 | | | | | | | | | | | | |
| b1265 - Optimism | 8,3 | | | | | | | | | | | | |
| b1300 - Energy and drive functions | 16,7 | X | X | | | | | | | | | | |
| b1301 - Energy level | 16,7 | X | X | | | | | | | | | | |
| b1304 - Motivation | 16,7 | X | X | | | | | | | | | | |
| b134 - Sleep functions | 8,3 | | | | | | | | | | | | |
| b140 - Attention functions | 8,3 | | | | | | | | | | | | |
| b144 - Memory functions | 16,7 | X | X | | | | | | | | | | |
| b152 - Emotional functions | 16,7 | X | X | | | | | | | | | | |
| b1522 - Range of emotion | 16,7 | X | X | | | | | | | | | | |
| b164 - Higher-level cognitive functions | 8,3 | | | | | | | | | | | | |
| b16700 - Reception of spoken language | 8,3 | X | | | | | | | | | | | |
| b16701 - Reception of written language | 8,3 | X | | | | | | | | | | | |
| b16702 - Reception of sign language | 8,3 | X | | | | | | | | | | | |
| b16710 - Expression of spoken language | 8,3 | X | | | | | | | | | | | |
| b16711 - Expression of written language | 8,3 | X | | | | | | | | | | | |
| b16712 - Expression of sign language | 8,3 | X | | | | | | | | | | | |
| b265 - Touch function | 8,3 | | | | | | | | | | | | |
| b270 - Sensory functions related to temperature and other stimuli | 16,7 | X | X | | | | | | | | | | |
| b2701 - Sensitivity to vibration | 8,3 | | | | | | | | | | | | |
| b2702 - Sensitivity to pressure | 8,3 | | | | | | | | | | | | |
| b2703 - Sensitivity to a noxious stimulus | 16,7 | X | X | | | | | | | | | | |
| b280 - Sensation of pain | 33,3 | X | X | X | | | | | | | | | |
| b28010 - Pain in head and neck | 8,3 | X | | | | | | | | | | | |
| b28016 - Pain in joints | 8,3 | X | | | | | | | | | | | |
| b440 - Respiration functions | 8,3 | | | | | | | | | | | | |
| b450 - Additional respiratory functions | 8,3 | X | | | | | | | | | | | |
| b5105 - Swallowing | 8,3 | X | | | | | | | | | | | |
| b525 - Defecation functions | 25 | X | X | X | | | | | | | | | |
| b5250 - Elimination of faeces | 16,7 | X | X | | | | | | | | | | |
| b5252 - Frequency of defecation | 8,3 | X | | | | | | | | | | | |
| b5253 - Faecal continence | 16,7 | X | X | | | | | | | | | | |
| b5350 - Sensation of nausea | 8,3 | X | | | | | | | | | | | |
| b6 - Genitourinary and reproductive functions | 16,7 | X | X | | | | | | | | | | |
| b620 - Urination functions | 33,3 | X | X | X | X | | | | | | | | |
| b6200 - Urination | 25 | X | X | X | | | | | | | | | |
| b6201 - Frequency of urination | 8,3 | X | | | | | | | | | | | |
| b6202 - Urinary continence | 33,3 | X | X | X | X | | | | | | | | |
| b7 - Neuromusculoskeletal and movement-related functions | 8,3 | X | | | | | | | | | | | |
| b710 - Mobility of joint functions | 8,3 | X | | | | | | | | | | | |
| b730 - Muscle power functions | 25 | X | X | X | | | | | | | | | |
| b7300 - Power of isolated muscles and muscle groups | 8,3 | X | | | | | | | | | | | |
| b7303 - Power of muscles in lower half of the body | 25 | X | X | X | | | | | | | | | |
| b7304 - Power of muscles of all limbs | 25 | X | X | X | | | | | | | | | |
| b7305 - Power of muscles of the trunk | 8,3 | X | | | | | | | | | | | |
| b735 - Power of muscles of the trunk | 16,7 | X | X | | | | | | | | | | |
| b7350 - Tone of isolated muscles and muscle groups | 8,3 | X | | | | | | | | | | | |
| b7353 - Tone of muscles of lower half of body | 8,3 | X | | | | | | | | | | | |
| b7354 - Tone of muscles of all limbs | 8,3 | X | | | | | | | | | | | |
| b740 - Muscle endurance functions | 8,3 | X | | | | | | | | | | | |
| b7800 - Sensation of muscle stiffness | 8,3 | X | | | | | | | | | | | |
Table 3 compares the occurrence of ICF categories for Activities and Participation in these functional evaluation instruments. Seventy-five ICF categories were linked in all the Activities and Participation chapters.

Table 3. ICF categories of the Activities and Participation component in instruments used for functional assessment of patients with non-traumatic spastic paraparesis

| COMPONENT ICF | % | FIM | OMNI | EDSS | FAIS | SCIM-3 | BI | SP-36 | ICA | SNPS | FSPH | GILETTE | SPROM |
|---------------|---|-----|------|------|------|--------|----|------|-----|------|-----|---------|-------|
| d155 - Acquiring skills | 83 | X | | | | | | | | | | | |
| d160 - Focusing attention | 83 | X | | | | | | | | | | | |
| d175 - Solving problems | 83 | X | | | | | | | | | | | |
| d177 - Making decisions | 83 | | | | | | | | | | | | |
| d20 - Undertaking multiple tasks | 83 | | | | | | | | | | | | |
| d230 - Carrying out daily routine | 167 | X | | | | | | | | | | | |
| d2301 - Managing daily routine | 83 | X | | | | | | | | | | | |
| d3 - Communication | 167 | X | | | | | | | | | | | |
| d310 - Communicating with - receiving - spoken messages | 83 | X | | | | | | | | | | | |
| d315 - Communicating with - receiving - nonverbal messages | 83 | X | | | | | | | | | | | |
| d320 - Communicating with - receiving - formal sign language messages | 83 | X | | | | | | | | | | | |
| d325 - Communicating with - receiving - written messages | 83 | X | | | | | | | | | | | |
| d330 - Speaking | 83 | X | | | | | | | | | | | |
| d335 - Speaking | 83 | X | | | | | | | | | | | |
| d4 - Mobility | 167 | X | | | | | | | | | | | |
| d410 - Changing basic body position | 167 | X | X | | | | | | | | | | |
| d4100 - Lying down | 83 | X | | | | | | | | | | | |
| d4102 - Kneeling | 83 | | | | | | | | | | | | |
| d4103 - Sitting | 167 | X | X | | | | | | | | | | |
| d4104 - Standing | 167 | X | X | | | | | | | | | | |
| d4105 - Bending | 83 | X | | | | | | | | | | | |
| d415 - Maintaining a body position | 83 | X | | | | | | | | | | | |
| d4153 - Maintaining a sitting position | 83 | X | | | | | | | | | | | |
| d420 - Transferring oneself | 333 | X | X | X | | | | | | | | | |
| d4200 - Transferring oneself while sitting | 83 | X | | | | | | | | | | | |
| d4201 - Transferring oneself while lying | 83 | X | | | | | | | | | | | |
| d430 - Lifting and carrying objects | 83 | X | | | | | | | | | | | |
| d4300 - Lifting | 83 | X | | | | | | | | | | | |
| d4301 - Carrying in the hands | 83 | X | | | | | | | | | | | |
| d4302 - Carrying in the arms | 83 | X | | | | | | | | | | | |
| d4351 - Kicking | 83 | X | | | | | | | | | | | |
| d440 - Fine hand use | 83 | X | | | | | | | | | | | |
| d445 - Hand and arm use | 167 | X | X | | | | | | | | | | |
| d4453 - Turning or twisting the hands or arms | 83 | X | | | | | | | | | | | |
| d450 - Walking | 75 | X | X | X | X | X | X | X | | | | | |
| d4500 - Walking short distances | 667 | X | X | X | X | X | X | X | | | | | |
| d4501 - Walking long distances | 25 | X | X | | | | | | | | | | |
| d4502 - Walking long distances | 83 | X | | | | | | | | | | | |
| d455 - Moving around | 25 | X | X | | | | | | | | | | |
| d4550 - Crawling | 167 | X | | | | | | | | | | | |
| d4551 - Climbing | 50 | X | X | X | X | X | X | X | | | | | |
| d4552 - Running | 25 | X | X | X | X | X | X | X | | | | | |
| d460 - Moving around in different locations | 83 | | | | | | | | | | | | |
| d4600 - Moving around within the home | 167 | X | X | | | | | | | | | | |
| d465 - Moving around using equipment | 583 | X | X | X | X | X | X | X | | | | | |
| d5 - Self-care | 167 | X | X | | | | | | | | | | |
| d510 - Washing oneself | 167 | X | X | | | | | | | | | | |
| d5100 - Washing body parts | 167 | X | X | | | | | | | | | | |
| d5101 - Washing whole body | 83 | X | | | | | | | | | | | |
| d5102 - Drying oneself | 167 | X | X | | | | | | | | | | |
| d520 - Caring for body parts | 167 | X | X | | | | | | | | | | |
| d5200 - Caring for skin | 167 | X | X | | | | | | | | | | |
| d5201 - Caring for teeth | 25 | X | X | X | | | | | | | | | |
| d5202 - Caring for hair | 333 | X | X | X | | | | | | | | | |
| d530 - Toileting | 25 | X | X | | | | | | | | | | |
| d5300 - Regulating urination | 83 | X | | | | | | | | | | | |
| d5301 - Regulating defecation | 167 | X | X | | | | | | | | | | |
| d5302 - Menstrual care | 83 | X | | | | | | | | | | | |
| d540 - Dressing | 25 | X | X | X | | | | | | | | | |
| d5400 - Putting on clothes | 333 | X | X | X | X | | | | | | | | |
| d5401 - Taking off clothes | 25 | X | X | | | | | | | | | | |
| d5402 - Putting on footwear | 87 | X | | | | | | | | | | | |
| d550 - Eating | 50 | X | X | X | X | X | | | | | | | |
| d560 - Drinking | 167 | X | X | | | | | | | | | | |
| d640 - Doing housework | 83 | X | | | | | | | | | | | |
| d6403 - Using household appliances | 83 | X | | | | | | | | | | | |
| d720 - Complex interpersonal interactions | 167 | X | X | | | | | | | | | | |
| d740 - Formal relationships | 167 | X | X | | | | | | | | | | |
| d7702 - Sexual relationships | 83 | X | | | | | | | | | | | |
| d850 - Remunerative employment | 167 | X | X | | | | | | | | | | |
| d9 - Community, social and civic life | 167 | X | X | | | | | | | | | | |
| d910 - Community life | 83 | X | | | | | | | | | | | |
| d920 - Recreation and leisure | 167 | X | X | | | | | | | | | | |
| d9201 - Sports | 83 | X | | | | | | | | | | | |
| d9205 - Socializing | 83 | X | | | | | | | | | | | |
Mobility (chapter d4) was the aspect mentioned in eleven of the instruments; with special importance for the categories Walking (d450), Walking short distances (d4500), Climbing (d4551), and Moving around using equipment (d465) which were mentioned more frequently, only the JOA doesn’t evaluate mobility. Self-Care (chapter d5) is the object of attention in seven instruments, including all the activities of daily living such as hygiene, dressing, feeding, toileting and body parts. The concept of independence was identified, either explicitly or implicitly in nine of the questionnaires and it is contained in General tasks and demands (d2) in four rating scales.

The Community, Social and Civic Life (d9) is present in FIM, FAMS e SF-36. The FIM and the EDSS were the scales that linked the most communication activities. Only the SF-36 evaluates the Doing Housework. The FAMS was the only instrument that evaluated sexual relations. Only the SF-36 evaluated the Mental Functions. Working was evaluated only by the FAMS and by the SF-36.

Table 4 shows the ICF categories for environmental factors. Twenty-one ICF categories were linked, encompassing all the chapters in this component, except Natural environment and human-made changes to environment (chapter e2). Assistive products and Technology (e1) was included in nine instruments, especially those that were geared towards mobility (e120) and assistive products and technology for mobility (e1201). Support and relationship (chapter e3) was also linked with five other instruments, especially Immediate family (e310) and Friends (e320).

It is necessary to point out that the instruments that value independence mentioned the help of others, but did not mention specifically who, therefore, it is not possible to distinguish whether they referred to family, friends, acquaintances, or formal personal assistants. The role of health services is highlighted by FAMS. The Environmental factors haven’t been evaluated by JOA.

| COMPONENT | ICF | FIM | OMDS | EDSS | FAMS | SCIM-3 | BI | SF-36 | JOA | SPMS | FSHSP | GILETTE | SSPROM |
|-----------|-----|-----|------|------|------|--------|----|-------|-----|------|-------|--------|--------|
| e1        | Products and technology           | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| e1100     | Drugs                              | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| e1500     | General products and technology for personal use in daily living | 25  | 8,3  | X    |      |        |    |       |     |      |        |        |        |
| e1510     | - Assistive products and technology for personal use in daily living | 33,3| X    | X    |      |        |    |       |     |      |        |        |        |
| e1200     | General products and technology for personal indoor and outdoor mobility and transportation | 41,7| X    | X    |      |        |    |       |     |      |        |        |        |
| e1201     | - Assistive products and technology for personal indoor and outdoor mobility and transportation | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| e1501     | Design, construction and building products and technology for gaining access to facilities inside buildings for public use | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| e1551     | Design, construction and building products and technology for gaining access to facilities in buildings for private use | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| e3        | Support and relationships          | 25  | 8,3  | X    |      |        |    |       |     |      |        |        |        |
| e310      | Immediate family                   | 16,7| X    | X    |      |        |    |       |     |      |        |        |        |
| e315      | Extended family                    | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| e320      | Friends                            | 16,7| X    | X    |      |        |    |       |     |      |        |        |        |
| e325      | - Acquaintances, peers, colleagues, neighbours and community members | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| e355      | - Health professionals             | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| e4        | - Attitudes                        | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| e410      | - Individual attitudes of immediate family members | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| e420      | - Individual attitudes of friends  | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| e425      | - Individual attitudes of acquaintances, peers, colleagues, neighbours and community members | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| e455      | - Individual attitudes of health-related professionals | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| e5801     | Health systems                     | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |

Only the JOA and SSPROM scored the body structures component, which corresponds to upper and lower ends and the shoulder region of the joints (Table 5). Of all the questionnaires used in this study, only SSPROM correlated with all components of the ICF, being more complete with regard to functioning.

Table 5. ICF Categories of the Body Structures component in instruments used for functional assessment of patients with non-traumatic spastic paraparesis

| COMPONENT | ICF | FIM | OMDS | EDSS | FAMS | SCIM-3 | BI | SF-36 | JOA | SPMS | FSHSP | GILETTE | SSPROM |
|-----------|-----|-----|------|------|------|--------|----|-------|-----|------|-------|--------|--------|
| s7200     | Bones of shoulder region           | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| s730     | - Structure of upper extremity     | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| s7301    | - Structure of upper arm           | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| s7302    | - Structure of forearm             | 8,3 | X    |      |      |        |    |       |     |      |        |        |        |
| s750     | - Structure of lower extremity     | 16,7| X    |      |      |        |    |       |     |      |        |        |        |

DISCUSSION

This study lists all the functional evaluation scales for non-traumatic paraparesis. In the literature, 12 functional evaluation instruments were identified for individuals with this health condition—among them, only the OMDS, SCIM-3, SPRS, FSHSP, SSPROM, JOA and Gilette could be considered specific. The remaining are either generic functional evaluation scales (FIM, BI) and were developed for other health conditions (EDSS: multiple sclerosis) or quality of life questionnaires related to health (FAMS, SF-36).

According to Post et al., the FIM, SF-36 and JOA scales are the most frequently used scales in studies of traumatic and non-traumatic spinal cord injury. The concepts of functioning and quality of life greatly overlap for they evaluate multiple domains that include activities of daily living, functional capacity, mobility, cognition, and social interaction.

However, while quality of life focus on the perception of the individual of his own satisfaction in these domains,30,31 the assessment of functioning can take this subjective aspect into consideration, but tries to make it more objective with more precise criteria or with the opinion of an observer.10

We could not link a reasonable part of the contents of the FAMS (55.9%) and SF-36 (56.6%) scales, which indicates a strong presence of personal factors, as one would expect from quality of life scales.
Also, although SPRS assesses the functional and motor performance of spastic paraparesis, 40.2% of their contents were not classified in ICF.

One of the multiple uses of the ICF is its capacity to translate concepts expressed in a variety of forms in various instruments into a single and standardized language. In this way, by translating the instruments identified in the literature for the ICF terms, it was possible to compare them and perceive their peculiarities. The simple overall comparison of the instruments shows that the FIM, the SUNNAS, and the FAMS include more ICF categories and are, therefore, more comprehensive. The overall comparison of the instruments shows that the FIM, the SCIM-3, SSPROM and FAMS address more ICF categories (Table 1) and should be considered more comprehensive.

Almeida noted that the SCIM-3 is more sensitive than the MIF ME compared to individuals with more independence. On the other hand, OMDS and Rankin scales have fewer ICF categories and are more restricted in their evaluations. On the other hand, FSHSP and OMDS contains less ICF categories, and are more stringent in their assessments.

Among the questionnaires used, nine evaluated the physiological body functions. Particular attention was given to muscle strength (b730, b7303, or b7304), which was mentioned in 58.3% of the questionnaires (Table 2), which is natural, since it is a typical physical problem in non-traumatic paraparesis. The functions related to Muscle Tone (b735) were found in SPRS and SSPROM, showing that other scales aren’t sensitive to this very frequent problem in paraparesis. Individuals with HTLV-1 associated myelopathy showed a lower FIM score for locomotion, sphincter control and bladder, personal care, and transfers. Pain was only evaluated by the FAMS, SF-36, JOA and SPRS scales, despite being frequently present in these patients, either due to spasticity, joint deformaties and biomechanical problems, or neuropathic characteristics.

The activities and participations express the result of interaction between intrinsic body capacity and personal and environmental factors. Thus, a person with paraparesis may have a severe vesical incontinence disability, but if properly trained and motivated and with access to the proper resources, this person can have an adequate performance in controlling urine, being able to notice his need to go to the bathroom, making the transfer, dealing with his clothing, using the drainage devices, and collecting the urine correctly.

Since the clinical manifestation of non-traumatic spastic paraparesis consists essentially of impairment of lower limb mobility, it was obvious that Walking (d450), as well as Moving around using equipment (d465) were activities evaluated by most instruments. Specifically regarding the different aspects of Walking (d4500, d4501) and Moving around (d4551, d465), the instrument that showed the most ICF categories were the OMS and Gilette, which gives it a distinct role when the intent is to evaluate the mobility of these individuals. The self-care activities are the next most frequently evaluated, but were only examined by the FIM, SCIM-3, BI.

Schepers et al. and Grill et al. observed that the FIM and the BI strongly correlated with chapters and d4 d5. Laxe et al. also found a high correlation between the FIM and the self-care activities. Post et al. also noted that the categories of chapters of mobility, as well as self-care appeared very often, and walking (d450) was the most cited second level category.

Two Brazilian studies applied the FIM scales to individuals with tropical spastic paraparesis and demonstrated the preferential impairment of strength in lower limbs, which limited their gait, feet care and dressing, transfers, and other activities that demand they remain standing on their feet. Despite the gait difficulties, the use of assistive devices for gait or a wheelchair was enough to obtain modified independence. Urine control was the second most impaired activity. The quality of life evaluation indicated problems in the social, physical, and emotional domains.

The concept of independence in performing tasks was identified either explicitly or implicitly in 75% of the questionnaires (Table 3), indicating the definitive participation that other people have in the functionality of these individuals. However, only the FAMS, Gillette, SPRS and SSPROM questionnaires specifically broached the question of who would be these third parties who act as assistants (Table 4). These questionnaires also evaluate the real influence on one’s independence of products for daily living, adapted or not, and resources to improve mobility, such as gait assistive devices, orthoses for the lower limbs, wheelchairs, and grab bars (Table 4).

Independence is an internationally considered concept in rehabilitation, since it has importance as a personal value, directly affects the family dynamics and income, and guarantees more social participation. The importance of health services was only evaluated by 8.3% of the instruments.

Although the individuals with disability and the common lay person may direct great attention to external signs of deformity, these instruments, as well as the opinion of health professionals and researchers is concerned with the tasks and actions that can be performed, so it is not a surprise that JOA and SSPROM are the only scales which evaluate body structures, like the structure of the shoulder region and upper and lower extremities. Also, we could show that any of the studied tools described Spinal Cord and Related Structures (s120). Although this information may be useful for diagnostic purposes, it adds very little in terms of functioning.

This study was restricted to the nominal comparison of the evaluation instruments’ contents, and was not able to indicate which would be most appropriate for clinical or classification purposes, since psychometric properties such as reproducibility, content specificity, sensitivity to clinical changes, and various aspects of validity were not compared.

CONCLUSION

Linking functional assessment questionnaires for spastic paraparesis to ICF allowed a comparison through a standardized and unifying terminology. The results allow researchers and clinicians interested in this health condition to choose the most appropriate instruments for their specific interests. Although it is recommended as a reference instrument in functional evaluation for this health condition, the FSHSP showed extreme limitations, both in its number of categories and in the ICF chapters approached.

The same can be said about the OMSDS instrument. FIM was the instrument that approached the most ICF categories and chapters, which gives it a specific role in the more global evaluation of these individuals.

However, FAMS was more successful in its approach of individual and social perspectives in environments and in the way people conduct their lives. It is necessary the development of other functional assessment tools for this health condition that encompasses all components of the ICF.

CONFLICT OF INTERESTS

The author(s) declare no conflict of interests.

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