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

6

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

10

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23

24 ABSTRACT

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

37

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

40

41 RESUMO

42 **Objetivo:** Identificar instrumentos utilizados para a avaliação funcional de pessoas com lesão
43 medular não-traumática (LMNT) e comparar seu conteúdo de acordo com os conceitos da CIF.
44 **Método:** A revisão sistemática foi realizada nas bases de dados Medline, Scielo, Pubmed e
45 Bireme com os descritores “paraparesia espástica”, “avaliação funcional”, “exame neurológico”,
46 “escalas neurológicas”, “avaliação neurológica” e “medidas de avaliação neurológica”. Para

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47 encontrar artigos relatando as escalas de avaliação funcional aplicadas em indivíduos com
48 LMNT. O conteúdo de tais instrumentos foi comparado após vinculá-los à CIF. **Resultados:** A
49 revisão sistemática identificou 12 instrumentos de avaliação funcional de LMNT, foram
50 identificadas 153 descrições das categorias da CIF, concentradas principalmente em: funções
51 neuromusculoesqueléticas, digestivas, atividades motoras e autocuidado. Entre os fatores
52 ambientais: a tecnologia assistiva para mobilidade, para uso pessoal na vida cotidiana, mereceu
53 maior atenção. **Conclusão:** Este estudo forneceu um guia para identificar instrumentos para
54 avaliar a funcionalidade de indivíduos com LMNT.

55
56 **Palavras-chave:** Classificação Internacional de Funcionalidade, Incapacidade e Saúde,
57 Traumatismos da Medula Espinal, Paraparesia Espástica, Inquéritos e Questionários,
58 Qualidade de Vida

59 60 INTRODUCTION

61
62 Non-traumatic spinal cord injuries include a group of varied etiology in which the most exuberant
63 clinical sign is the spastic paraparesis, predominantly of lower limbs with insidious beginning,
64 slow progression, associated with varied degrees of sensory and sphincter impairment.^{1,2,3} It
65 can occur due to some diseases such as hemorrhages, tumors, viral infections, and vascular
66 and degenerative alterations, as well as spinal malformations, secondary vertebral subluxations,
67 rheumatoid arthritis, or degenerative joint disease.^{4,5,6}

68
69 In addition to giving attention to the deficiencies of physiological functions, the rehabilitation
70 intervention requires the observation of the individual's performance in meaningful tasks in his
71 life experience, according to the environment in which he or she lives. Thus, a comprehensive
72 evaluation presupposes the observation of all of these aspects. In the specific case of non-
73 traumatic paraparesis, the most frequently recommended functional evaluations are the Osame
74 Motor Disability Scale (OMDS)⁷ and the Functional Independence Measure (FIM).⁸

75
76 The ICF was published by the WHO in 2001 to describe the functioning and relevant contextual
77 factors in the life experiences of people. It reformulates concepts uniting the medical and social
78 models in the understanding of disability and it can be used to obtain an interaction of various
79 health dimensions such as the individual, social, and biological.⁹ In order to render its practical
80 and routine use viable, ICF-based instruments have been developed for clinical use¹⁰ and for
81 public policies.¹¹ By supplying a universal and standardized language, it can be used as a tool
82 to compare functional evaluation instruments, since the concepts present in these instruments
83 can be translated into a common language.¹²

84
85 Clinical manifestations of traumatic and non-traumatic spinal cord injuries are very similar, in
86 order to identify more specific aspects of functioning we conducted a literature review based on
87 functional assessment measures for spastic paraparesis of non-traumatic etiology.

88 89 OBJECTIVE

90
91 The objective of this study was to list the instruments used in the functional evaluation of
92 individuals with non-traumatic paraparesis in the scientific literature and to compare their
93 contents using the ICF as a reference standard. We prioritized the use of the validation articles
94 in the study original language.

95 96 METHODS

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

102

103 **Identification of the functional evaluation measurements in non-traumatic spastic** 104 **paraparesis and their link with the ICF**

105

106 The keywords used in this search were: 'spastic paraparesis', 'transverse myelitis', 'non-
107 traumatic spinal cord injury', 'functional evaluation', 'paraparesis', 'neurological evaluation',
108 'neurological evaluation measurements', 'questionnaires', 'functioning', and 'quality of life'. The
109 articles that discussed non-traumatic spinal cord injury, regardless of etiology, diagnosed by
110 neurological, image, or functional exams met the inclusion criteria. All the study designs were
111 considered, as long as they included the use of functional evaluation instruments. Instruments
112 that evaluated only one limited aspect of physiological functions such as only pain, diuresis,
113 strength, or immunological aspects were not considered. The instruments in question needed
114 to include activities or participations that are understood by the ICF as the performance of tasks
115 by an individual or his involvement in life situations.

116

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

121

122 Linking significant contents of the evaluation instruments to ICF followed the recommendations
123 described by Cieza,¹³ categorizing them as a body function, anatomical structure, activity or
124 participation or environmental factor. Although not classified in ICF, the concepts were linked to
125 personal factors or other concepts, like quality of life. We always sought out the category that
126 best described the significant content present in the evaluation instrument, thus, there was no
127 limitation regarding the level of classification in ICF. Following the above recommendations,
128 whenever an instrument's significant content was identified as either "other, specified" or "not
129 specified," the category in the level immediately above was preferred over those which codes
130 ended with 98 or 99, respectively.

131

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

136

137 **RESULTS**

138

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

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147 OMDS, SCIM-3, SPRS, FSHSP, JOA, Gillette e SSPROM could be considered specific for non-
148 traumatic spastic paraparesis.

149

150 Table 1 compares the overall contents of instruments. FIM was the instrument with the greatest
151 number of ICF categories. It also shares 20.6% of its ICF categories with other instruments, and
152 13.5% of the categories are exclusive, guaranteeing a distinct role in the functional evaluation
153 of individuals with non-traumatic spastic paraparesis. On the other hand, easy to read and quick
154 to apply instruments such as the OMDS and FSHSP stand out for presenting the lowest number
155 of ICF categories, which shows their limitation for a more comprehensive evaluation.

156

157 The FAMS is the scale with the most exclusive categories, which are not seen in the other scales
158 (11.6%) and there are a great number of personal factors such as “embarrassment in public
159 places” or “feeling ill,” reflecting the concept of quality of life related to health — that is, the
160 personal opinion of the individual about his own health experience (WHO-QL, 1998). In this
161 instrument, 19 (55.8%) of the 34 significant contents identified could not be linked to the ICF
162 categories, either because they referred to quality of life or to personal factors, or because they
163 were not contained in the classification.¹³

164

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

167

Abbreviation of rating scales	ICF categories		
	Total	Shared	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
GILETTE	13	12	1
SSPROM	34	22	12

168

169 Table 2 shows the occurrence of ICF categories of the Body Functions in each of these
170 instruments. Fifty ICF categories were identified and represented six chapters. Pain sensation
171 (b280), Urination functions (b620) and Urinary continence (b6202) were the most linked
172 categories. However, when the categories were grouped under their respective chapters, the
173 neuromusculoskeletal functions and those related to movement were mentioned in seven
174 instruments; functions for mental in three, genitourinary and digestive system in six instruments;
175 sensory functions in five, and cardiorespiratory in only one, and no instrument verified the
176 functions of voice, speech, skin and related structures. Pain is evaluated in general, in the

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b2702 - Sensitivity to pressure	8,3									X
b2703 - Sensitivity to a noxious stimulus	16,7							X		X
b280 - Sensation of pain	33,3			X		X	X	X		
b28010 - Pain in head and neck	8,3			X						
b28016 - Pain in joints	8,3			X						
b440 - Respiration functions	8,3					X				
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
b6201 - Frequency of urination	8,3								X	
b6202 - Urinary continence	33,3					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

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d2301 - Managing daily routine	8,3				X	
d3 - Communication	16,7	X		X		
d310 - Communicating with - receiving - spoken messages	8,3	X				
d315 - Communicating with - receiving - nonverbal messages	8,3	X				
d320 - Communicating with - receiving - formal sign language messages	8,3	X				
d325 - Communicating with - receiving - written messages	8,3	X				
d330 - Speaking	8,3	X				
d335 - Speaking	8,3	X				
d4 - Mobility	16,7	X				X
d410 - Changing basic body position	16,7		X		X	
d4100 - Lying down	8,3	X				
d4102 - Kneeling	8,3					X
d4103 - Sitting	16,7	X				X
d4104 - Standing	16,7	X				X
d4105 - Bending	8,3					X
d415 - Maintaining a body position	8,3		X			
d4153 - Maintaining a sitting position	8,3					X
d420 - Transferring oneself	33,3	X	X	X		X
d4200- Transferring oneself while sitting	8,3					X
d4201- Transferring oneself while lying	8,3		X			
d430 - Lifting and carrying objects	8,3					X
d4300 - Lifting	8,3					X
d4301 - Carrying in the hands	8,3					X
d4302 - Carrying in the arms	8,3					X

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d4351 - Kicking	8,3							X				
d440 - Fine hand use	8,3						X					
d445 - Hand and arm use	16,7			X			X					
d4453 - Turning or twisting the hands or arms	8,3											X
d450 - Walking	75	X	X	X	X			X	X	X	X	X
d4500 - Walking short distances	66,7	X	X	X			X	X	X	X	X	X
d4501 - Walking long distances	25						X	X			X	
d4502 - Walking long distances	8,3										X	
d455 - Moving around	25		X				X					X
d4550 - Crawling	16,7		X					X				
d4551 - Climbing	50	X	X				X	X	X		X	
d4552 - Running	25		X						X		X	
d460 - Moving around in different locations	8,3						X					
d4600 - Moving around within the home	16,7						X				X	
d465 - Moving around using equipment	58,3	X	X	X			X	X			X	X
d5 - Self-care	16,7	X		X								
d510 - Washing oneself	16,7							X	X			
d5100 - Washing body parts	16,7	X					X					
d5101 - Washing whole body	8,3	X										
d5102 - Drying oneself	16,7	X					X					
d520 - Caring for body parts	16,7			X				X				
d5200 - Caring for skin	16,7	X					X					
d5201 - Caring for teeth	25	X					X	X				
d5202 - Caring for hair	33,3	X					X	X				X

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d530 - Toileting	25	X		X	X		
d5300 - Regulating urination	8,3	X					
d5301 - Regulating defecation	16,7	X				X	
d5302 - Menstrual care	8,3			X			
d540 - Dressing	25			X	X	X	
d5400 - Putting on clothes	33,3	X		X		X	X
d5401 - Taking off clothes	25	X		X			X
d5402 - Putting on footwear	8,7			X			
d550 - Eating	50	X	X	X	X	X	X
d560 - Drinking	16,7	X		X			
d640 - Doing housework	8,3					X	
d6403 - Using household appliances	8,3					X	
d720 - Complex interpersonal interactions	16,7	X					X
d740 - Formal relationships	16,7	X					X
d7702 - Sexual relationships	8,3			X			
d850 - Remunerative employment	16,7			X		X	
d9 - Community, social and civic life	16,7	X		X			
d910 - Community life	8,3	X					
d920 - Recreation and leisure	16,7			X		X	
d9201 - Sports	8,3					X	
d9205 - Socializing	8,3	X					

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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 to mobility (e120) and assistive products and technology for mobility (e1201).

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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

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225

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	SPRS	FSHSP	GILETTE	SSPROM
s7200 - Bones of shoulder region	8,3								X				
s730 - Structure of upper extremity	8,3												X
s7300 - Structure of upper arm	8,3								X				
s7301 - Structure of forearm	8,3								X				
s7302 - Structure of hand	8,3								X				
s750 - Structure of lower extremity	16,7								X				X

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Only the JOA and SSPROM scored the body structures component, which corresponds to upper and lower ends and the shoulder region of the joints.

Of all the questionnaires used in this study, only SSPROM correlated with all components of the ICF, being more complete with regard to functioning.

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 Gillette 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.³² 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,^{33,34} 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

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251 expect from quality of life scales. Also, although SPRS assesses the functional and motor
252 performance of spastic paraparesis, 40.2% of their contents were not classified in ICF.
253

254 One of the multiple uses of the ICF is its capacity to translate concepts expressed in a variety
255 of forms in various instruments into a single and standardized language. In this way, by
256 translating the instruments identified in the literature for the ICF terms, it was possible to
257 compare them and perceive their peculiarities. The simple overall comparison of the instruments
258 shows that the FIM, the SUNNAS, and the FAMS include more ICF categories and are,
259 therefore, more comprehensive. The overall comparison of the instruments shows that the FIM,
260 the SCIM-3, SSPROM and FAMS address more ICF categories (Table 1) and should be
261 considered more comprehensive.
262

263 Almeida³⁵ noted that the SCIM-3 is more sensitive than the MIF ME compared to individuals
264 with more independence. On the other hand, OMDS and Rankin scales have fewer ICF
265 categories and are more restricted in their evaluations. On the other hand, FSHSP and OMDS
266 contains less ICF categories, and are more stringent in their assessments.
267

268 Among the questionnaires used, nine evaluated the physiological body functions. Particular
269 attention was given to muscle strength (b730, b7303, or b7304), which was mentioned in 58.3%
270 of the questionnaires (Table 2), which is natural, since it is a typical physical problem in non-
271 traumatic paraparesis.^{1,36,37} The functions related to Muscle Tone (b735) were found in SPRS
272 and SSPROM, showing that other scales aren't sensitive to this very frequent problem in
273 paraparesis. Individuals with HTLV-1 associated myelopathy showed a lower FIM score for
274 locomotion, sphincter control and bladder, personal care, and transfers.³⁸ Pain was only
275 evaluated by the FAMS, SF-36, JOA and SPRS scales, despite being frequently present in these
276 patients, either due to spasticity,^{1,36,37} joint deformities and biomechanical problems,^{2,37} or
277 neuropathic characteristics.^{1,36,37,39,40}
278

279 The activities and participations express the result of interaction between intrinsic body capacity
280 and personal and environmental factors. Thus, a person with paraparesis may have a severe
281 vesical incontinence disability, but if properly trained and motivated and with access to the
282 proper resources, this person can have an adequate performance in controlling urine, being able
283 to notice his need to go to the bathroom, making the transfer, dealing with his clothing, using
284 the drainage devices, and collecting the urine correctly.
285

286 Since the clinical manifestation of non-traumatic spastic paraparesis consists essentially of
287 impairment of lower limb mobility, it was obvious that Walking (d450), as well as Moving around
288 using equipment (d465) were activities evaluated by most instruments. Specifically regarding
289 the different aspects of Walking (d4500, d4501) and Moving around (d4551, d465), the
290 instrument that showed the most ICF categories were the OMDS and Gillette, which gives it a
291 distinct role when the intent is to evaluate the mobility of these individuals. The self-care activities
292 are the next most frequently evaluated, but were only examined by the FIM, SCIM-3, BI.
293

294 Schepers et al.⁴¹ and Grill et al.⁴² observed that the FIM and the BI strongly correlated with
295 chapters and d4 d5. Laxe et al.⁴³ also found a high correlation between the FIM and the self-
296 care activities. Post et al.³² also noted that the categories of chapters of mobility, as well as self-
297 care appeared very often, and walking (d450) was the most cited second level category.
298

299 Two Brazilian studies applied the FIM scales to individuals with tropical spastic paraparesis and
300 demonstrated the preferential impairment of strength in lower limbs, which limited their gait, feet

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301 care and dressing, transfers, and other activities that demand they remain standing on their feet.
302 Despite the gait difficulties, the use of assistive devices for gait or a wheelchair was enough to
303 obtain modified independence. Urine control was the second most impaired activity.^{37,40} The
304 quality of life evaluation indicated problems in the social, physical, and emotional domains.⁴⁰

305
306 The concept of independence in performing tasks was identified either explicitly or implicitly in
307 75% of the questionnaires (Table 3), indicating the definitive participation that other people have
308 in the functionality of these individuals. However, only the FAMS, Gillette, SPRS and SSPROM
309 questionnaires specifically broached the question of who would be these third parties who act
310 as assistants (Table 4). These questionnaires also evaluate the real influence on one's
311 independence of products for daily living, adapted or not, and resources to improve mobility,
312 such as gait assistive devices, orthoses for the lower limbs, wheelchairs, and grab bars (Table
313 4).

314
315 Independence is an internationally considered concept in rehabilitation, since it has importance
316 as a personal value, directly affects the family dynamics and income, and guarantees more
317 social participation.^{7,23} The importance of health services was only evaluated by 8.3% of the
318 instruments.³²

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

326
327 This study was restricted to the nominal comparison of the evaluation instruments' contents,
328 and was not able to indicate which would be most appropriate for clinical or classification
329 purposes, since psychometric properties such as reproducibility, content specificity, sensitivity
330 to clinical changes, and various aspects of validity were not compared.

331 332 **CONCLUSION**

333
334 Linking functional assessment questionnaires for spastic paraparesis to ICF allowed a
335 comparison through a standardized and unifying terminology. The results allow researchers and
336 clinicians interested in this health condition to choose the most appropriate instruments for their
337 specific interests. Although it is recommended as a reference instrument in functional evaluation
338 for this health condition, the FSHSP showed extreme limitations, both in its number of categories
339 and in the ICF chapters approached.

340
341 The same can be said about the OMDS instrument. FIM was the instrument that approached
342 the most ICF categories and chapters, which gives it a specific role in the more global evaluation
343 of these individuals. However, FAMS was more successful in its approach of individual and
344 social perspectives in environments and in the way people conduct their lives. It is necessary
345 the development of other functional assessment tools for this health condition that encompasses
346 all components of the ICF.

347 348 **CONFLICT OF INTERESTS**

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350 The author(s) declare no conflict of interests.

351

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