ORIGINAL ARTICLE

Development of the Spanish version of the Barry-Albright Dystonia Scale: translation, cross-cultural adaptation and determination of reliability and validity of content in Mexican patients with dyskinetic cerebral palsy. Pilot study

Desarrollo de la versión en español de la Escala de Distonía de Barry-Albright: traducción, adaptación transcultural y determinación de la fiabilidad y validez de contenido en pacientes mexicanos con parálisis cerebral discinética. Estudio piloto

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Keywords:

dyskinetic cerebral palsy, dystonia, Barry-Albright Dystonia scale, translation, Mexican patients.

Palabras clave:

parálisis cerebral discinética, distonía, escala para distonía de Barry-Albright, traducción, pacientes mexicanos.

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Introduction: dystonia is an abnormal pattern of posture and/or involuntary, uncontrolled, recurrent, occasionally stereotyped movement, Barry-Albright Dystonia Scale (BADS) is one of the most useful clinical tools to measure dystonia in children with cerebral palsy. There is no Spanish version of a scale that measures dystonia. Objective: to develop the Spanish Barry-Albright Dystonia Scale (BADS) and evaluate the inter and intrarater reliability of the scale and to measure its validity in the Mexican population with dyskinetic cerebral palsy. Material and methods: we developed the Spanish version of the BADS for children with dyskinetic cerebral palsy in the Mexican population by the forward and backward translation procedure and testing for acceptability and the clarity of item wording so that the scale could be used by Spanish-speaking examiners. The studies included the validity of content (using Delphi method by a panel of experts), inter and intrarater reliability which were examined by 2 raters in 30 videos of patients with dyskinetic cerebral palsy twice on two occasions using the spanish BADS. Results: the intrarater and interrater reliability was very good for the Spanish BADS (Pearson correlation coefficient > 0.90) with a statistically significant agreement between raters and within raters (all p < 0.001), the scale also translated into Spanish, obtained a high content validity index (I-CI 0.82-0.94). Conclusions: the spanish version of the Barry-Albright Dystonia Scale showed high content value, as well as adequate inter and intrarater reliability. The scale constitutes an understandable, viable, simple and useful instrument.



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Resumen

Introducción: la distonía es un patrón anormal de la postura o movimientos ocasionalmente estereotipados, involuntarios, sin control y recurrentes. La escala para distonía de Barry-Albright (BADS), es una de las herramientas de mayor uso para medir la distonía en niños con parálisis cerebral. No hay alguna escala en español para medir la distonía. Objetivo: desarrollar la versión en español de la BADS para niños mexicanos con parálisis cerebral discinética. Material y métodos: desarrollamos la versión en español de la escala BADS a través del procedimiento de traducción y retrotraducción y prueba de la misma, para conocer su aceptación y la claridad de los reactivos y pueda ser utilizada por examinadores de habla española. Los estudios incluyeron la validez de contenido (usando el método Delphi con un panel de expertos), la fiabilidad inter e intraobservador en 30 vídeos de pacientes con parálisis cerebral discinética, examinados por dos observadores, dos veces en dos ocasiones, utilizando la BADS en español. Resultados: la fiabilidad intra e interobservador fue muy buena para la BADS en español (Coeficiente de correlación de Pearson > 0.90) con significancia estadística inter e intraobservadores (todas las p < 0.001), también la escala traducida obtuvo índice de validez de contenido alto (I-IC 0.82-0.94). Conclusiones: la versión en español de la escala para distonía de Barry-Albright mostró alta validez de contenido, así como adecuada fiabilidad inter e intraobservador. La escala constituve un instrumento útil, viable, simple y de fácil comprensión.

INTRODUCTION

Cerebral palsy (CP) is the major cause of physical disability in the pediatric population and it persists into adulthood.¹ The global prevalence of CP discussed is generally of 2.11 cases per 1,000 live births.² The specific rate in low- and middle-income countries is unclear, but it has every indication of being higher, there are more prominent contagious illness rates, prebirth and perinatal consideration contrasts and lack of rehabilitation services, causing more terrible long term physical disability.³ According to the National Health Program 2001-2006 the precise information in Mexico's incidence is not available, but there is a cerebral palsy register of 12 000 cases per year. Disability constitutes a serious public health problem. It is estimated that 2.3% of the Mexican population suffer from severe disability.⁴ Recently the specialists presented the term «high risk of cerebral palsy» from those cases where the few distinguishable risk factors, probably including hereditary conditions, connect between each other, driving a precise prediction before a half year's corrected age.^{5,6} The Surveillance of Cerebral Palsy in Europe (SCPE) classifies CP into the following four subtype groups: spastic (bilateral and unilateral), dyskinetic (dystonic and choreoathetotic), ataxic and non-classifiable; all placed in decreasing order.^{7,8} The different motor types of CP may emerge and change during the first 5 years of life, in the Australian population the major prevalence is the spastic form with 81-92%, followed by dyskinetic type in 3-9%, then ataxic in 3-6%; and hypotonic (0-4%), which is not classified in all countries.⁸ Swedish reports established up to 15% of dyskinetic cerebral palsy (DCP).⁹ The clinical assessment of the muscle tone of a child is imperative to differentiate between spasticity, dystonia, rigidity or a combination of these; all distinctive forms of hypertonia.^{10,11}

DCP involves two major movement disorder patterns: dystonia, which refers to: «abnormal postures, involuntary twisting, and repetitive movements due to sustained or intermittent muscle contractions».⁹ At the point when several abnormal movement patterns coincide, the SCPE recommend us to call it «mixed CP forms» and to mainly classify it by the predominant clinical component.^{12,13} DCP can have numerous causes and motor impairments are often more severe in people with DCP than in patients with other types of cerebral palsy; such as non-motor comorbidities include intellectual impairment, anarthria, and epilepsy, affecting daily living skills.^{10,14-17} Sensorial disabilities, visual and hearing, are also common.¹¹

To measure the level of dystonia when it is generalized is difficult.^{18,19} Stewart et al. made a precise review of clinical scales to measure dystonia as well as choreoathetosis in children with CP and relying upon certain met standards, they focused on 6 papers which will be cited: «Burke-Fahn-Marsden Dystonia Rating Scale (BFMDRS), Barry-Albright Dystonia Scale (BADS), Unified Dystonia Rating Scale (UDRS), Movement Disorder-Childhood Rating Scale (MD-CRS), Movement Disorder-Childhood Rating Scale (MD-CRS), Movement Disorder-Childhood Rating Scale 0-3 years (MD-CRS 0-3), and Dyskinesia Impairment Scale (DIS)".^{13,20} All of these assess dystonia, but BADS is by all accounts the most well-established and most used clinical tool. It was initially created for individuals with secondary dystonia including CP and seems to exhibit responsiveness to change following certain interventions, it evaluates eight body regions. An upper score demonstrates more noteworthy seriousness of dystonia, specific preparation to use the scale is not required, one only needs to be familiar with the clinical description it mentions, it is the least intricate and best scale, which is good for day by day clinical use.¹⁰ In the original study made by Barry et al. the interrater reliability for the eight item scores by 13 raters for 10 patients utilizing the intraclass correlation coefficient (ICC) went from 0.061 to 0.866, the unwavering quality for the complete score was 0.866.¹⁸ A study compared BADS with BFMDRS and UDRS and concluded the interrater reliability of BADS was moderate to good and internal consistency was high.¹¹ As is notorious there are few scales, in general, most health scales are created in English-speaking nations, the culturally diverse adjustment of a wellbeing status survey for use in another country, culture, and language needs a controlled method. The term «crosscultural adaptation» is used to include interpretation and social adjustment issues.¹⁹ The 5 steps that must be followed in order to protect the sensibility of the tool in the objective culture are: I) «Translation», II) «Back translation», III) «Committee review», IV) «Pre-testing» and V) «Weighting of scores». It is not generally possible to follow all the steps portrayed here because of the structure of the measure.¹⁸ The right interpretation and social adjustment of a questionnaire doesn't generally ensure the conservation of its psychometric properties, so it is important to continue the process by measuring the reliability and validity in the target language.²¹ So DCP is one of the most disabling forms of CP, it is probably the most common presentation of dystonia in children; there is no Spanish version of a scale that measures dystonia. Due to the importance of the diagnosis and the early approach of dyskinetic cerebral palsy, it is necessary to have simple clinical tools which can be administered by any health professional who performs pediatric assessments. Therefore, this study aimed to develop the Spanish BADS and evaluate the interrater and intrarater reliability of the scale and to measure its content validity in the Mexican population with dyskinetic cerebral palsy at the Instituto Nacional de Rehabilitación «Luis Guillermo Ibarra Ibarra» (INRLGII).

The translation of this scale is of special interest because all Spanish speakers can use it and benefit from it, as well as to unify criteria for the study of the patients and to objectively measure the possible changes after a therapeutic program.

MATERIAL AND METHODS

This was a prospective, clinical measurement study for translation, cross-cultural adaptation, determination of validity of content and inter- and intrarater reliability of the Spanish BADS in Mexican patients with DCP. We included patients with a diagnosis of DCP (dystonic, choreoathetoid or mixed forms) from the Pediatric Rehabilitation Department of the INRLGII when they came for their medical appointments. The patients were between 3 and 18 years of age. The data of the patients were collected the first time they attended the INRLGII. Gender, age, comorbidities, dyskinetic cerebral palsy type, intellectual coefficient and the Gross Motor Function Classification System (GMFCS) were the variables studied. Patients with dystonia of doubtful etiology or attributable to causes other than forms of secondary dystonia were excluded from the sample. The final sample consisted of 30 participants. The study was approved by the INRLGII ethical committee, with registration number 12/19. The parents signed the informed consent. The raters were two physiatrists, both experts in pediatric rehabilitation. Neither had used the scale before conducting this study, they were familiarized with the translated item descriptions before applying it to the evaluations. The procedure used to establish the Spanish version of the BADS was the forward-backward translation method described by Guillemin et al. (Supplementary: Appendix A). Two direct translations were made from the original instrument (source language, English) to the language destination (Spanish). Translators have different profiles, they are bilinguals, one was familiarized with the concepts of cerebral palsy, and the other was the native translator working from the original instrument as with translator versions 1 and 2. A synthesis of these translations which was made was later translated again to the original language. After that a review procedure was carried out where the authors of the study agreed about the semantic and conceptual equivalence, because this assessment is an instrument used by health professionals.

To measure the reliability of the translated scale, a 4-minute video register was made of the participants (after signing the informed consent by the parent or legal guardian), 2 minutes focusing on the face and neck, and 2 more minutes to evaluate the trunk and the 4 limbs. Raters registered the dystonic movement scores for each patient using the translated scale. For the intrarater reliability study, the same two raters reassessed the video-patients 2 weeks apart using the same procedure. The raters were blinded to each other's scores and did not have access to their previous scores. The psychometric testing included the validity of content, the Delphi method was used. A group of 9 professionals with a 5-year minimum experience in the care of children with CP participated electronically. An e-mail with a brief questionnaire was sent to evaluate their experience accumulated in the diagnosis, evaluation and therapeutic management of DCP and finally their skills using international instruments for the evaluation of dystonia. A measurement was made of the coefficient of knowledge, argumentation and competition. The multidisciplinary panel was formed by 6 different professionals involved in the scope of pediatric disability, including neurologists, pediatricians and physiatrists. Regarding the region of work, there were Mexican and Colombian experts. They rated 3 videos randomly using Spanish BADS and notified if they agreed on the item scores and total score compared with the punctuations from ours. The content validity index (I-CVI) was obtained by dividing the number of experts who rated the item with a 1 (very adequate), 2 (quite adequate) and 3 (adequate) among the total number of experts for each of the items and the total score of the Spanish BADS.

Statistical analysis. Descriptive statistics were applied to determine the demographic characteristics of the sample, the content validity index was considered satisfactory for values greater than 0.70, the inter and intrarater reliability was determined using the Pearson correlation coefficient, taking p < 0.05 as statistically significant. Stata SE Software 6.0 was used.

RESULTS

Thirty patients with DCP (based on clinical history, observation and physical examination) (male 60%, female 40%) were studied. There were no sample losses. The mean age was 5.7 years (SD 3.90, range 3-17). The predominant motor pattern of DCP was mixed type in 21 patients (70%), dystonic type in 8 patients (26.6%) and choreoathetosis in one patient (3.33%). All 100% of the participants had affectation in all 4 limbs, 93.3% were GMFCS IV and V, only 2 patients in the sample (6.66%) were ambulatory. An evaluation of intellectual function was made depending on the patient's age using Peabody Picture Vocabulary Test and Wechsler Intelligence Scale for Children-IV by a psychologist who also rated adaptive skills. 18 patients (60%) had intellectual disability and in 36.6% of the sample (11 patients) it was not possible to determine the intellectual function because of the age. Only in 3.3% (1 patient) the intellectual function was normal. The non-motor comorbidities reported were underweight (3 patients), 9 patients (30%) had diagnosis of epilepsy, 1 patient had history of soft tissue surgery and 2 patients had history of soft tissue and bone surgery, 7 patients had hearing loss (*Table 1*).

Interrater reliability. The results showed significant agreement between two raters (p < 0.001) obtaining a high Pearson's correlation coefficient (0.90). Interrater reliability obtained on both occasions was very good. Using Pearson's correlation coefficient the results indicated very good intrarater reliability for both raters (p < 0.001) (*Table 2*).

Table 3, shows the measurement of different criteria for the reproducibility and validity of the translated scale.

There was a consensus among the experts and those responsible for the study (*Table 4*), note the results obtained in the individual items and in the total score box. The columns of categories 1 (very adequate), 2 (quite adequate) and 3 (adequate) resulted in the majority of responses from the experts, with minimal or no selection for columns 4 (not adequate) and 5 (inadequate). The study showed a high content validity index of the scale with scores between 0.82 and 0.94 in all items including the total score.

DISCUSSION

Documenting the wide range of functional limitations and disability due to dystonic movements in cerebral palsy is challenging for health professionals. Valid and reliable instruments are indispensable for the correct evaluation. It is known in the academic field that most of the clinical scales are developed in English-speaking countries. The development of the Spanish version of the BADS has been based on the translation and cultural adaptation guidelines ensuring consistency in the content and face validity between the original English version and the Spanish BADS. To the best of our knowledge, this is the first study of a Spanish translation and adaptation of this tool and we have not found other translations into other languages.

The BADS's creators improved the requirement for a clinical appraisal instrument that considered the differed physical and cognitive impairments of people with cerebral palsy and traumatic brain injury, trying to determine the changes resulting from an intervention (application of intrathecal baclofen).¹⁸ To date it is still considered the most useful clinical tool for measuring dystonia in children with CP, Stewart et al. indicated that: «the BADS is the least complex and quickest scale, which is favorable for clinical use, although it lacks insight into choreoathetosis».¹³ For its development, a video recording was taken of 18 patients with CP and TBI (a very heterogeneous sample of patients between the ages of 3 to 42 years), with meetings of 20-45 minutes relying upon the degree of participation, versatility and useful abilities of the patient.¹⁸

In our hospital as in other international publications, DCP is the second motor pattern in frequency, spasticity is the most common, the majority of our population lack the ability to walk and have intellectual disability. Our video recording was 4 minutes to make it applicable in the outpatient clinic of cerebral palsy; initially at rest and then performing a variety of functional activities (those measured by the scale). The translated scale retained all characteristics of the original tool; however, this process encountered few difficulties, but all of them had a good resolution. The Spanish BADS was easy to understand, and it was accepted well by those responsible for the study and the group of experts. The results were characterized as very good in the different psychometric properties of inter- and intrarater reliability. When applying the scale in pediatric patients, the results were similar to the original study (with high reliability in the total

Table 1: Demographic characteristics,	GMFCS,	EDACS, MACS,	CFCS from	the patients.
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	GMFCS				
Characteristics	I(n = 0)	II (n = 2)	III $(n = 0)$	IV (n = 4)	V (n = 24)
Age range Gender, (percentage)		3-17		3-16	3-14
Girls (40%)		8		8	83
Boys (60%)		11		16	77
Intelligence quotient		1 NV		3 NV	7 NV
		$1 \le 69$		$1 \le 69$	$16 \le 69$
					$1 \ge 80$
CP type, n (%)					
1 Mix		1 (100)		1 (50)	1 (70)
2 Dystonic				2 (50)	2 (25)
3 Choreoathetotic					3 (4)
EDACS, n (%)		1 (EO)			1 (4)
		T (50) 2 (50)		2 (100)	1 (4)
		2 (30)		2 (100)	2 (37)
					3 (30) 4 (8)
Level 5					+ (0)
MACS, n (%)					
1					1 (4)
11		2 (100)		4 (100)	9 (37)
III					12 (50)
IV					2 (8)
V					
CFCS, n (%)		NV (50)		NV (75)	NV (33)
Level I					1 (4)
Level II					
Level III		1 (50)		1 (25)	2 (8)
Level IV					10 (41)
Level V					3 (12)

GMFCS = gross motor function classification system. EDACS = eating and drinking ability classification system. MACS = manual ability classification system. CFCS = communication function classification system. NV = not valued.

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RUL = right upper limb. LUL = left upper limb. RLL = right lower limb. LLL = left lower limb. Total score coding: 1 = subtle 1-3 points (10%). 2 = mild 4-16 points (11-49%). 3 = moderate 17-29 points (50-89%). 4 = severe 30-32 points (90-100%).

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VI 28	- m 0 0	VA 28	7 17 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7
27 27	0 1	VA 27	0 0 0 0
VI 26	6 7 7 7 7 7 7 7 7 7 7	VA 26	7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7
VI 25	6 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7	VA 25	7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7
24 KI	3 3 3 5 5 5 4 5 5 5 5 5 5 5 5 5 5 5 5 5 5	VA 24	3 4 3 3 5 5 5 4 5 5 5 5 5 5 5 5 5 5 5 5 5
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22 22	1 0 0 1 1 1 1 0 0 0 1 1	VA 22	0 0 0 1 1 0 0 0 0
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12 K	0 1 7 1 7 1 7 1 0 1 0 7 1 0 1 0 1 0 1 0 1 0 1 0 1 0 1 0 1 0 1	VA 12	0 0
⇒ 1	0 0 0 0	4A 11	0 0 ∞ 0
10	0 - 0 0 - 0 4 4 6 6	VA 10	0 - 0 - 0 - 4 4 6 7
VI 9	3 , 3, 3, 3, 3, 4, 3, 4, 3, 7, 3, 7, 7, 7, 7, 7, 7, 7, 7, 7, 7, 7, 7, 7,	VA 9	00 2 4 4 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7
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Neck Trunk RUL LUL RLL LLL LLL Total **Severity**

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scores, but not for the individual items), an interobserver reliability of 0.90 and intraobserver reliability of 0.99 were obtained for the total score using Pearson correlation, and with the participation of the experts' committee, the scale achieved adequate content validity.

An important weakness of the scale is that it lacks the evaluation of choreoathetosis unlike the DIS. However due to multiple advantages already mentioned, it was decided to work with BADS in the first instance. An important part of the sample of patients evaluated were diagnosed with mixed type cerebral palsy with a predominance of spasticity over dystonic movements. The sample size was decided based on other validation studies. We suggest the creation of a new scale that addresses both dystonia and choreoathetosis in patients with dyskinetic CP, in a way that allows evaluation with short videos that contain functional movements showing the difference between the different abnormal movements and sufficiently to discriminate dystonia, spasticity and choreoathetosis. The clinical quantification and classification of dystonic CP is important not only to adapt the appropriate treatments that lead to better results, if not to avoid ineffective or even harmful treatments. When dystonia is the predominant motor type, its severity may be such that it masks coexisting features of spasticity. This scale would help establish a functional prognosis regarding the length of time dystonia is present as well as the interference with the patient's function or care. It is necessary to have an instrument designed to evaluate the therapeutic efficacy of different medications as well as treatment models for the patient with dystonia, the availability of this instrument will allow us to continue an in-depth study of the pathology and evaluate the effects in the mid and long term of influence of therapeutic interventions.^{22,23}

CONCLUSION

We can conclude the Barry-Albright Dystonia Scale in its Spanish version constitutes an understandable,

Table 3: Psychometric evaluation of spanish Barry Albright Dystonia Scale.

Criterion	Property	Statistical	Results	
Reproducibility	Reliability	Cronbach's alpha coefficient	0.89	
	Internal consistency reliability	Spearman's rank correlation	0.84	
	Test-retest reliability	Pearson's correlation coefficient	0.99 0.99	
	Inter-rater reliability		0.90 (p = 0.00001)	
Validity	Face validity	Applicability and acceptability	Adequate	
	Content validity	Analysis	See Table 2	
	Criterion validity	Pearson's correlation coefficient	0.99	

Table 4: Content validity index (I-CVI) of the experts who participated in the study.

S´BADS items	1. Very adequate n (%)	2. Quite adequate n (%)	3Adequate n (%)	4. Few adequate n (%)	5Inadequate n (%)	I-CVI
Eyes	9 (52.94)	6 (35.29)	1 (5.88)	0.00	1 (5.88)	0.94
Mouth	10 (58.82)	2 (11.7)	2 (11.7)	3 (17.64)	0.00	0.82
Neck	5 (29.41)	8 (47.05)	3 (17.64)	0.00	1 (5.88)	0.94
Trunk	5 (29.41)	5 (29.41)	4 (23.52)	2 (11.7)	1 (5.88)	0.82
RUL	6 (35.29)	10 (58.82)	0.00	1 (5.88)	0.00	0.94
LUL	10 (58.82)	4 (23.52)	1 (5.88)	1 (5.88)	1 (5.88)	0.88
RLL	8 (47.05)	2 (11.7)	4 (23.52)	2 (11.7)	1 (5.88)	0.82
LLL	6 (35.29)	5 (29.41)	4 (23.52)	1 (5.88)	1 (5.88)	0.88
Total	5 (29.41)	4 (23.52)	7 (41.17)	0.00	1 (5.88)	0.94

S'BADS = Spanish version Barry Albright Dystonia Scale. RUL = right upper limb. RLL = right lower limb. LUL = left upper limb. LLL = left lower limb.

viable, simple and useful instrument, however, it failed to discriminate other clinical variants of dyskinetic cerebral palsy. The validation of clinical instruments with evidence for the diagnosis, treatment and prognosis of children with cerebral palsy may be useful in future studies.

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