TITLE: RELIABILITY AND VALIDITY OF TURKISH VERSION OF CHILDREN'S HAND USE

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RELIABILITY AND VALIDITY OF TURKISH VERSION OF CHILDREN'S HAND USE EXPERIENCE QUESTIONNAIRE FOR CHILDREN WITH HEMIPARETIC CEREBRAL PALSY

Mahsum EREN [1], Gamze Ekici [2] , Halil ALKAN [3]

Abstract

Purpose: Cerebral Palsy (CP) is a non-progressive lesion in the developing brain due to prenatal, perinatal and postnatal causes; however, it is a permanent motor function, posture and movement development disorder that can change with age. Our aim in this study is to investigate the cross-cultural adaptation, validation and reliability of Children's Hand-use Experience Questionnaire (CHEQ).

Methods: Ninety-five children between 6 and 18 years of age with hemiparetic Cerebral Palsy (CP) were included in this study. Gross Motor Function Classification System (GMFCS) was used to determine their motor levels, Manual Ability Classification System (MACS) was used to determine their manual ability, Pediatric Evaluation of Disability Inventory (PEDI) was used to determine their disability level and Children's Hand-use Experience Questionnaire (CHEQ) was used to determine their hand use ability.

Results: Investigating reliability of CHEQ, 35 children with hemiparetic CP were evaluated 1week interval. The test-retest reliability was described by using intra-class correlation coefficient (ICC). Convergent and divergent construct validities were assessed by examining the Spearman's correlation coefficients of the CHEQ compared to MACS and GMFCS and PEDI. Reliability were tested by using ICC and found to be 1.00. The 'activities performed independently' section of the CHEQ had statistically significant and good correlations (p=0.001) with the MACS and the self-care section of the PEDI. It had statistically significant but weak correlation (p=0.001) with the GMFCS

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Introduction

Cerebral Palsy (CP) is a non-progressive lesion in the developing brain due to prenatal, perinatal and postnatal causes; however, it is a permanent motor function, posture and movement development disorder that can change with age (Swaiman, Ashwal, & Ferriero, 2006). The motor disorders that occur in CP show limited joint movements especially in the upper extremity, isolated finger and thumb movements which cannot be performed in normal pattern, and grip problems (Levitt & Addison, 2018). Children with CP often have difficulty in activities of daily living that require the use of two hands as a result of the affected upper extremity function (Sköld, Josephsson, & Eliasson, 2004).

Hand functions are an essential component to perform activities of daily living and other functions (Jonsson & Larsson, 1990). Evaluation of hand function and performance is important in defining the skill level of the individual in daily living activities, the effectiveness of rehabilitation and demonstrating the person's role skills. Because the inadequacy of hand functions affect the performance of daily activities, work and leisure time activities (Yücel & Akı, 2007).

The scales used in hand and wrist evaluations usually focus on the range of motion, strength and sensation. However, these methods do not assess the subjective factors that affect the outcome, such as pain, skills, participation in activities of daily life and return to work, which enable the individual to maintain his/her daily life (Changulani, Okonkwo, Keswani, & Kalairajah, 2008). In addition to being aim oriented, the scales used should be sensitive to children's development process, cultural structure and changes in general life level. For this reason, valid and reliable scales translated into the language of the study population should be used (Waters et al., 2009). When the literature is examined, there are widely used assessment tools and classification systems for upper extremity in children with CP (Sršen, 2012; Wagner, Davids, & Research®, 2012). The Children's Hand Use Experience Questionnaire (CHEQ) is a questionnaire developed for children aged between 6 and 18 with functional limitation in one hand (Sköld, 2010). The CHEQ can be presented to the participants in the form of an output or as an internet based application (www.cheq.se). The aim of this study is to investigate the Turkish version, validity and reliability of CHEQ in children with Hemiparetic CP.

Materials and methods

Participants

This study was carried out in 95 children with Hemiparetic CP between the ages of 6 and 18 in various special education centers. In order to conduct the study, ethics committee approval was obtained by Hacettepe University Non-invasive Clinical Research Ethics Commission with project number G0 13 / 239-10. Sample size was determined according to statistical power analysis procedures by using Power Analysis and Sample Size software.

Measurements

Prior to the study, all children and their families were informed about the study and the participants were signed an informed consent form. Sociodemographic information of the children (age, gender, weight, height, body mass index (BMI), affected side), motor function levels, manual skills classification, disability levels and hand use experiences were recorded by one-to-one interviews with children and their families.

Gross Motor Function Classification System

In the assessment of the functional level of children with CP, the Gross Motor Function Classification System (GMFCS) was used, which had a Turkish version and differentiated children according to their age. The GMFCS is a common classification system tool of five levels ranging from level I, which includes children with minimal or no disability with respect to community mobility, to level V, which includes children who are totally dependent on external assistance for mobility (Palisano, Rosenbaum, Bartlett, Livingston, & Neurology, 2008).

Manual Ability Classification System

The Manual Ability Classification System (MACS) was used to classify hand skills of children. MACS uses a five-level scale to describe how children with CP handle objects in daily life. Level I indicates independence in handling objects in everyday life with only minor difficulty, whereas children at level V need assistance in handling all objects in activities of daily life (Akpinar, Tezel, Eliasson, Icagasioglu, & rehabilitation, 2010). MACS cannot evaluate the hands separately when evaluating the participation of both hands together in daily life (Eliasson et al., 2006). The Turkish validity and reliability study of MACS was carried out previously by Akpinar et al. (Akpinar et al., 2010).

Pediatric Evaluation of Disability Inventory

Pediatric Evaluation of Disability Inventory (PEDI) questionnaire, which is applied to families, was used to evaluate the functional ability and performance of children with CP. The PEDI includes three sets of measurement scales: Functional Skills, Caregiver Assistance, and Modifications. The Functional Skills Scales were designed to sample meaningful subtasks of a set of complex functional activities. The Caregiver Assistance Scale is a evaluate of the extent of help the caregiver provides in typically daily situations. The Modifications Scale is a evaluate of environmental modifications and equipment used by the child in daily activities. Each individual scale is designed to capture a different aspect of the child's function in selfcare, mobility and social function domains. The PEDI consists of 197 functional skill items, and 20 items that evaluate caregiver assistance and modifications (Uyanık & Tural, 2003). PEDI's Turkish validity and reliability study was conducted previously by Erkin et al. (Erki̇ n et al., 2007).

The Children's Hand Use Experience Questionnaire

The CHEQ questionnaire was used to evaluate the hand experience of children with CP. The CHEQ evaluates the child's experience of using the affected hand in bimanual activities. It was developed for children aged 6–18 years with hemiparetic CP, upper limb reduction deficiency, and obstetric brachial plexus palsy. When responding to the questionnaire, participants are asked whether the activity in the questionnaire is perform independently. If activities can be carried out independently, the activities are questioned whether one or two hands are used. If two hands are used during activities, grasp efficacy, the time taken to perform the activity compared with peers (time consumption), and the experience of feeling bothered while performing the activities independently (feeling bothered) are questioned and scoring is given (Sköld, Hermansson, Krumlinde Sundholm, & Eliasson, 2009).

In the study, after obtaining permission for the Turkish version of CHEQ to be adapted to Turkish, World Health Organization (WHO)'s standard protocol was applied to adapt the scales to different languages. The pilot study was conducted by applying CHEQ to 35 children with hemiparetic CP.

Statistical analysis

Statistical analyses were performed using IBM Statistical Package for the Social Science software version 20. The analyzes were performed using nonparametric statistical methods. The data distribution was performed using the Shapiro-Wilk test and the total type-1 error level was accepted as 5% and the p-value as smaller than 0.05 for statistical significance. Categorical variables were expressed as number and percentage value, while numerical variables were expressed as mean ± standard deviation. In the arithmetic means, 95% confidence interval (CI) was calculated with the formula 95% CI = mean ± 1.96 x standard error. Reliability was tested with 2-sided random effective intraclass correlation coefficient (ICC) and presented with 95% CIs. ICC was interpreted as excellent reliable ≥ 0.80, moderately reliable = 0.60 - 0.79, low reliable <0.60 (Richman, Makrides, & Prince, 1980). Divergent and convergent construct validities of the activities in CHEQ were tested using the Spearman correlation coefficient (rho) (Martin, Engelberg, Agel, & Swiontkowski, 1997) in comparison with the MACS, GMFCS and PEDI. Content validity was evaluated by considering the asymmetric effect in content distribution, ceiling and floor. In our study, asymmetric statistic rate was tested between -1 and +1, and the effect of floor and ceiling were hypothesised below 15% (Terwee et al., 2007).

Findings

The descriptive characteristics of the children included in the study are given in Table 1.

Table 1. Descriptive characteristics of the children with hemiparetic CP (n=95)

			n (%)
Gender		Boys	53 (55.8)
		Girls	42 (44.2)
Affected side		Left hand	48 (50.5)
		Right hand	47 (49.5)
GMFCS		Level I	2 (2.1)
		Level II	76 (80.0)
		Level III	7 (7.4)
		Level IV	4 (4.2)
		Level V	6 (6.3)
MACS		Level I	1 (1.1)
		Level II	50 (52.6)
		Level III	30 (31.6)
		Level IV	13 (13.7)
		Level V	1 (1.1)
			X ±SD
CHEQ	**Performing activities**	Performed independently	17.9±7.2
		Not performed independently	6.7±6.4
		Not applicable	4.2±5.4
	Using the affected hand	Holding the object	2.4±3.8
		Supporting without holding the object	15.2±7.9

		Not applicable	0.7±1.3
	Experience of using the affected hand	Grasp efficacy	2.4±0.3
		Time taken	2.1±0.4
		Feeling bothered	2.1±0.4
PEDI	**Functional Skills**	Self-care	50.9 ± 12.6
		Mobility	40.2 ± 10.0
		Social Function	50.5 ± 10.9
		Total score	141.0 ± 31.5
	Caregiver Assistance	Self-care	21.7 ± 8.1
		Mobility	20.4 ± 7.7
		Social Function	18.7 ± 4.9
		Total score	60.8 ± 19.2
Age (years)			12.1 ± 4.2
BMI (kg/m2)			20.8 ± 4.2

CP: Cerebral Palsy; CHEQ: Children's Hand Use Experience Questionnaire; PEDI: Pediatric Evaluation of Disability Inventory; GMFCS: Gross Motor Function Classification System; MACS: Manual Ability Classification System; BMI: Body mass index; SD: Standart sapma

The CHEQ items applied to children with hemipretic CP and observed values are given in Table 2.

Table 2. The CHEQ items applied to children with hemipretic CP and observed values.

CHEQ items	Performing activities			Using the affected hand		
	Performed independently n (%95 CI)	Not performed independenty n (%95 CI)	Not applicable n (%95 CI)	Supporting without holding the object n (%95 CI)	Holding the object n (%95 CI)	N appli n (%9
1. Fasten a necklace (whilst around the neck)	9 (4.2-16.8)	38 (30.5-49.5)	48 (40-60)	9 (100-100)	-	
2. Tie shoelaces	19 (11.6-28.4)	40 (31.6-52.6)	36 (28.4-48.4)	17 (73.7-100)	2 (0-26.3)	
3. Peel an orange	21 (13.7-31.6)	44 (36.8-56.8)	30 (22.1-41.1)	18 (71.4-100)	3 (0-28.6)	
4. Buckle a helmet (for example a bike-helmet)	27 (20-36.8)	29 (22.1-40)	39 (31.6-51.6)	25 (81.5-100)	2 (0-18.5)	
5. Take off the protective plastic backing of a Elastoplast	27 (20-36.8)	43 (35.8-55.8)	25 (16.8-34.7)	23 (70.4-96.3)	4 (3.7-29.6)	
6. Button up the trousers	35 (27.4-47.3)	34 (26.3-45.3)	26 (17.9-36.8)	28 (65.7-94.2)	4 (2.9-22.9)	3 (0
7. Cut meat (or other food hard to cut up) on a plate	37 (28.4-48.4)	36 (28.4-47.4)	22 (14.7-31.6)	33 (78.4-97.3)	4 (2.7-21.6)	
8. Cut out a picture using scissors	41 (32.7-53.7)	32 (24.2-43.2)	22 (14.7-31.6)	35 (73.2-95.1)	5 (2.4-22.0)	1 (0
9. Cut on a chopping board (for example fruit, vegetables, bread)	41 (34.0-53.2)	32 (25.5-43.6)	21 (13.8-30)	37 (80.5-97.6)	4 (2.4-19.5)	
10. Handle playing-cards (Refers to the whole process; holding, selecting and placing cards in the hand while playing)	53 (46.3-66.3)	19 (12.6-27.4)	23 (15.8-33.7)	49 (84.9-98.1)	4 (1.9-15.1)	
11. Put toothpaste on a toothbrush	55 (47.4-67.4)	30 (22.1-41.1)	10 (5.3-16.8)	49 (80.0-96.1)	5 (1.8-18.2)	1 (0
12. Carry a tray (for example in the canteen)	56 (48.4-68.4)	30 (22.1-41.1)	9 (4.2-15.8)	53 (87.5-100)	3 (0-12.5)	
13. Put on socks	57 (50.5-69.5)	28 (20-37.9)	10 (4.2-16.8)	49 (75.4-94.7)	5 (1.8-15.8)	3 (0-
14. Open up a box of milk or juice	57 (49.5-70.5)	27 (20-37.9)	11 (5.3-18.9)	46 (70.2-91.2)	11 (8.8-29.8)	
15. Butter a slice of soft bread	60 (53.7-73.7)	29 (21.1-40.0)	6 (2.1-11.69)	49 (71.7-90)	10 (8.3-26.7)	1 (0
16. Cut a pancake (or other food easy to cut up) on the plate	63 (55.8-75.8)	21 (13.7-31.6)	11 (5.3-17.9)	50 (69.4-88.7)	8 (4.8-22.6)	5 (1.6
17. Remove a straw from the front of a juice box and insert it (Refers to the whole process, including taking off the wrapping of the straw)	71 (66.3-83.2)	15 (8.4-23.2)	9 (4.2-15.8)	61 (77.5-93)	10 (7.0-22.5)	
18. Pull up the zipper of a jacket	72 (67.4-84.2)	17 (10.5-26.3)	6 (2.1-11.6)	59 (72.2-91.6)	12 (8.3-26.4)	1 (0
19. Open a small box (for example a box of mints)	72 (67.4-84.2)	17 (10.5-26.3)	6 (2.1-11.6)	65 (83.3-97.2)	6 (2.8-15.3)	1 (0
20. Open a bag (for example a bag of crisp)	76 (71.6-87.4)	17 (10.5-26.3)	2 (0-5.3)	67 (80.3-94.7)	8 (3.9-17.1)	1 (0
21. Remove the wrapping from an ice-cream	76 (72.3-89.4)	15 (8.5-24.4)	3 (0-6.4)	68 (81.6-96.1)	8 (3.9-18.4)	

22. Screw off the cap of a small, unopened softdrink bottle	80 (76.8-90.5)	12 (6.3-20.0)	3 (0-6.3)	60 (65.0-83.8)	20 (16.3-35.0)	
23. Pull up track suit trousers	85 (83.2-94.7)	6 (2.1-11.6)	4 (1.1-8.4)	65 (67.1-85.9)	9 (4.7-17.6)	11 (5
24. Pick money out of a purse or wallet	86 (84.2-95.8)	7 (2.1-12.6)	2 (0-5.3)	70 (73.3-89.5)	16 (10.5-26.7)	
25. Open the zipper on a small bag (e.g pencil case or purse)	86 (84.2-95.8)	5 (1.1-10.5)	4 (1.1-8.4)	74 (77.9-93)	10 (5.8-18.6)	2 (0
26. Open a plastic box with a lid (for example an ice-cream box)	86 (84.2-96.8)	4 (1.1-8.4)	5 (1.1-10.5)	72 (75.6-91.8)	12 (7.0-20.9)	2 (0
27. Eat out of a small container of yoghurt	88 (87.4-97.9)	6 (2.1-11.6)	1 (0-3.2)	64 (62.5-81.8)	19 (13.6-30.7)	5 (1.1
28. Remove the wrapping from a piece of candy	89 (88.4-97.9)	6 (2.1-11.6)	-	64 (61.8-80.9)	7 (3.4-13.5)	18 (12.
29. Spread out glue on paper using a glue stick	93 (94.7-100)	1 (0-3.2)	1 (0-3.2)	77 (74.2-90.3)	16 (9.7-25.8)	

Test–retest reliability of CHEQ in children with hemiparetic CP is given in Table 3.

Table 3. Test–retest reliability for CHEQ in children with hemiparetic CP (n=35)

		ICC	%95 CI
Performing activities	Performed independently	1.00	0.99—1.00
	Not performed independenty	0.99	0.98—1.00
	Not applicable	0.97	0.95—0.99
Using the affected hand	Holding the object	0.96	0.93—0.98
	Supporting without holding the object	0.99	0.99—1.00
	Not applicable	1.00	1.00—1.00
Experience of using the affected hand	Grasp efficacy	0.99	0.97—0.99
	Time taken	0.99	0.97—0.99
	Feeling bothered	0.98	0.96—0.99

CP: Cerebral Palsy; CHEQ: Children's Hand Use Experience Questionnaire; ICC: intraclass correlation coefficient; CI: confidence interval.

The relationship between the number of performed activities in CHEQ activities and MACS, GMFCS, PEDI is given in Table 4.

Table 4. The relationship between the number of performed activities in CHEQ and MACS, GMFCS, PEDI (n=95)

The number of performed activities in CHEQ		MACS	GMFCS	PEDI				
				FS-sc	FS-m	FS-sf	FS-t	CA-sc
Performed independently	r	-0.80	-0.48	0.82	0.70	0.58	0.78	0.66
	p	0.001	0.001	0.001	0.001	0.001	0.001	0.001
Not performed independenty	r	0.50	0.15	- 0.50	-0.42	-0.36	-0.47	-0.37
	p	0.001	0.001	0.001	0.001	0.001	0.001	0.001
Not applicable	r	0.22	0.25	-0.29	-0.21	-0.13	-0.25	-0.24
	p	0.036	0.017	0.004	0.040	0.214	0.016	0.017

CP: Cerebral Palsy; CHEQ: Children's Hand Use Experience Questionnaire; GMFCS: Gross Motor Function Classification System; MACS
Pediatric Evaluation of Disability Inventory; FS-sc: Functional Skills-self care; FS-m: Functional Skills-Mobility; FS-sc: Functional Skills -Soc
CA-sc: Caregiver Assistance-self care; CA-m: Caregiver Assistance-Mobility; CA-sc: Caregiver Assistance-Social Function; CA-t: Caregiver Ass

Asymmetric statistical value was found as 0.31, ceiling and floor effects were found as 4.2% and 1.1% respectively in activities performed independently in CHEQ.

There was a excellent relationship statistically between activities performed independently in CHEQ and MACS, Functional Skills-self care scores while a low relationship was found between activities performed independently in CHEQ and GMFCS scores.

Discussion

The results show that the Turkish version of CHEQ is a valid, reliable, appropriate tool for use in children with hemiparetic CP. In addition, it was observed that children with Hemiparetic CP had moderate grasp efficacy, moderate feeling bothered in their hands, and performed activities longer than their peers.

Scale adaptation studies are considered to be advantageous because it provides cheaper, easier to speak same language with literature than new scale development (Bicer, Yazici, Camdeviren, Erdogan, & rehabilitation, 2004). In the scale adaptation studies, it is emphasized that it is important not only to make translation, but also the purpose of the scale translated, the conceptual and cultural conformity version to be in harmony with the target country (Waters et al., 2009). In scale adaptation studies, we applied CHEQ's Turkish adaptation according to the protocol of WHO's five-stage protocol to adapt the scales to different languages.

A newly developed or translated scale need to fulfill the validity and reliability. It is known that the most widely used validity criteria are content validity, predictive validity, and construct validity (Karasar, 1999). Content validity is made in order to determine whether the whole of the scale and its sub-sections measure the area to be measured, and whether they contain different concepts outside the area to be measured (Küçükdeveci et al., 2004). We determined that the content validity of CHEQ to Turkish was found as a result of the test-retest performed on the children with Hemiparetic CP (Table 3). The construct validity is defined as the degree of measurement of a test that measures a property that cannot be measured directly (Karasar, 1999). In order to test this section, the comparison method with a measuring tool previously known it's validity is used. In our study, the construct validity of CHEQ in children with hemiparetic CP was compared and tested with MACS, GMFCS and PEDI measurement tools, and the relationships between them were statistically significant (Table 4). Based on these results, it was found that CHEQ was a valid questionnaire for clinicians and researchers in the field of pediatric rehabilitation to be used routinely in hemiparetic CP assessment.

At different times, when the same measurement tool is applied to the individuals, the similarity of the responses of the individuals to the items in the measurement tool shows the invariance of the that measurement tool. This is considered to be an indicator that the scale is reliable (Karasar, 1999). Another important point is the standard ICC score used to evaluate test-retest reliability (Erefe, 2002). ICC; It is one of the methods used to determine reliability in scale development and cultural adaptation studies, and this value is expressed as ≥ 0.80 for excellent reliability, moderate reliability for 0.60 - 0.79 and low reliability for <0.60 (Richman et al., 1980). In our study, families' working hours and children's status were taken into consideration and retesting was carried out one week later. Thus, ICC values of CHEQ's

test-retest scores were over 0.95. This result showed that CHEQ is a reliable questionnaire that can be used easily in the clinic.

It is stated that children with hemiparetic CP avoid using affected hands (Greaves, Imms, Dodd, Krumlinde-Sundholm, & Neurology, 2010) and use affected hands only for support purposes (Pagliano et al., 2001). In a study, when the rate of those who performed the activity independently was found to be high, the proportion of those using the affected hand as grasping and support was observed to be moderate (Hermansson, Skold, & Eliasson, 2013). In our study, 18 of the 29 activities in the CHEQ were carried out independently by children with hemiparetic CP. The rate of children using the affected hand in grasping was low and the ratio of those who using as a support was high. Similar to the study above, the results in our study also showed that children with Hemiparetic CP avoided using their affected hands actively and used it more in supportive activities.

The CHEQ is questioned the grasp efficacy, time consumption according to peers and the experience of feeling bothered during activity in children with functional limitation in one hand (Sköld et al., 2009). Ekblom et al. (Ekblom et al., 2013), in their study using CHEQ, were found to be high children's grasp efficacy, time consumption according to peers and the experience of feeling bothered during activity. Similarly, Sköld et al (Sköld et al., 2009). also questioned the grasp efficacy, time consumption and the experience of feeling bothered in children with functional limitation in one hand when performing activity and found the results to be high according to the their peers. In the same study, they reported that the most independent group was children with obstetric brachial plexus and the most dependent group was children with Hemiparetic CP in terms of participation in activities. They also stated that the most difficult activity was fasten a necklace (whilst around the neck). In our study, it was determined that the grasp efficacy was moderately affected, the time consumption was twice according to peers and the experience of feeling bothered was moderate during activities in children with hemiparetic CP. The results of our study in children with Hemiparetic CP were moderate because of the neurological lesion at early stages of life, which may affect the motor planning and cognition areas (Hermansson et al., 2013). We also observed that the most difficult activity by children with Hemiparetic CP was fasten a necklace (whilst around the neck). The other two most difficult activities are; "the tie shoelaces" and "peel the an orange" activities. In addition to these, three activities that children with Hemiparetic CP have found the easiest; "eat out of a small container of yoghurt", "remove the wrapping from a piece of candy" and "spread out glue on paper using a glue sticks".

Conclusion

The Turkish version of CHEQ is a valid, reliable, appropriate tool for use in children with hemiparetic CP. Children with hemiparetic CP can use their affected hands to participate in activities. These children had moderate grasp efficacy, moderate feeling bothered in their hands, and performed activities longer than their peers.

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