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INVESTIGATING THE RELIABILITY, VALIDITY, AND SENSITIVITY OF THE SCALES ASSESSING HEALTH RELATED QUALITY OF LIFE AND FUNCTIONAL HEALTH STATUS IN CEREBRAL PALSY

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ABSTRACT

Background: Cerebral palsy (CP) is the most common cause of physical disability in children and it causes many problems such as motor, sensory and cognitive impairment, and it leads to effect child's quality of life. There are many of questionnaire for evaluating quality of life but which is reliable, valid and sensitive to age groups children with CP in Turkish. Our study aims to investigate whether the Pediatric Outcomes Data Collection Instrument (PODCI), Pediatric Quality of Life Inventory (PedsQL) and Child Health Questionnaire Parent Form (CHQ PF-50) scales are reliable, valid, and sensitive in children with Cerebral Palsy among different age groups and impairment levels.

Methods: 105 children with CP, 48 healthy children and their mothers were participated in this study. They were divided into three groups according to their age; as 2-7 years, 8-12 years and 13-18 years. Statistical power analysis was conducted to acquire statistical power at a medium level (80%).

Results: The internal consistency of scales was acceptable and their test-retest reliability was significant (for PODCI, α=0.93 and ICC=0.992, for PedsQL α=0.85 and ICC=0.955, for CHQ PF-50 α=0.92 and ICC=0.975). The findings of their validity indicated that they were significantly sensitive in discriminating healthy children and children with CP ($p<0.001$). However, the scales could only distinguish age and GMFCS groups in physical functioning domain ($p<0.05$).

Conclusions: Within the concept of our study, the PODCI, PedsQL, and CHQ PF-50 scales were found reliable, valid, and sensitive in children wıth CP between ages 2-18. The sections regarding the physical functioning domains of these three scales presented sensitive results in accordance with the age and GMFCS levels of the children with CP.

Keywords: Cerebral Palsy, Functional Health Status, Health Related Quality of Life, PedsQL, PODCI, CHQPF-50

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INTRODUCTION

Cerebral Palsy (CP), is the most common cause of physical disability in children, is a non-progressive neurological impairment results from an injury in developing brain and causes various neuromuscular and cognitive disabilities [1, 2, 3]. It also leads to multiple problems that affects functionality and psychosocial health of children and adolescents, so they do not able to play roles on their family, school, and other environments. Thus, rehabilitation aims to improve functional health status and increase independence in daily life, school, and social environment which are very crucial for the CP treatment.

Health-related Quality of Life (HRQOL) is defined as physical, psychological, and social effects on different areas of health status which changes according to the person's experiences, beliefs, expectations, and perception. It indicates how parents and children perceive the effects of a disability and its treatment. United Cerebral Palsy Association (UCPA) emphasizes the importance of the HRQOL by adopting the mission statement "to positively affect the quality of life of children with CP" in 1991 [4]. Thus, the assessment of the HRQOL which indicates the level of a person's physical, psychological, and social status and the effects of the CP on daily life activities are required in order to organize and perform a successful rehabilitation program.

Since it is thought that conventional clinical assessment outcomes are not related to the well-being status of a child alone [5, 6, 7], various QOL scales have been improved. The quality of life scales which were developed specific for CP include the CPCHILD with parents form, the PedsQL-CP and the DISABKIDS-CP modules with parents forms CP QoL-Child with both child and parents forms [8, 9]. Although the reliability of these scales is significant, their use is limited because of multiple health problems of children with CP. So HRQOL scales are more commonly preferred for children with CP. Moreover, HRQOL scales can be completed by the parents if children have problems with cognition, communication, perception or if they are not literate [10]. Today the PODCI (measuring the functional status of children and adolescents), the CHQ PF-50(assessing functional health and well-being status), the Lifestyle Assessment Questionnaire (LAQ) (determining the effects of disability), and the PedsQL (focusing on the functional health) are the most frequently used reliable and valid scales [8, 9, 11- 14].

Most of developed QOL scales are in English, so translating them into another languages and investigating reliability and validity for that language is required to make their use more common. Cristakou and Laiou reported that studies indicating the reliability, validity and sensitivity of the QOL scales used in the CP population and translated in the original languages are necessary [15]. In consequence, this study aims to investigate the reliability, validity, and sensitivity of the Turkish versions of the scales PODCI, CHQ PF-50 and PedsQL which can be used to designate the QOL levels of the children with CP in different age groups living in Turkey.

MATERIALS AND METHODS

1. Participants

105 children with Cerebral Palsy (CP), aged between 2 and 18 years, were observed by separating into three different age groups; 2-7, 8-12, and 13-18 years. 2-9 year-old children's mothers were asked to complete the scales. Children, who were between 10 and 18 years old and able to read and understand the questions, were asked to complete the forms for themselves.

Informed consent: Informed consents approved by the Hacettepe University Ethical Committee were obtained from the mothers of each child (LUT 09/68).

2. Measurements

Demographic and socioeconomic characteristics of sample, that included children with CP, healthy children and their mothers who live in Ankara, were recorded.

Children with CP were classified into three groups according to gross motor function levels measured by the Turkish Version of the Gross Motor Function Classification System (GMFCS) [16]. The first group included GMFCS level one and two, the second group included level three and the third group included level four and five.

The Turkish Versions of the PODCI [17], PedsQL [18], and CHQ PF-50 [19] scales were given in a closed envelope to children with CP and their mothers. Mothers were also informed verbally. For the age group 2-7 years, 50 forms were given to mothers of the children with CP and 30 forms to the mothers of healthy children. 50 forms were given to both mothers and their children with CP in the age groups of 8-12 years and 13-18 years, whereas 30 forms were given to both mothers and their children in the healthy group. The participants were asked again to complete unmarked (new) forms three days after first completion. Incomplete and false marked forms among the collected forms were excluded from the data analysis.

3. Statistical Analysis

Statistical analysis was performed using SPSS software version 15 for Windows. Demographic and socioeconomic status, age groups and the distribution according to the GMFCS levels of the children with CP and healthy children were calculated as numbers and percentages (%).

Cronbach alpha coefficients and test-retest correlations (Pearson and Intraclass Correlation Coefficient - ICC) were calculated to assess the reliabilities of the PODCI, CHQ PF-50 and PedsQL scales and also to observe the internal consistency and test-retest correlations of the scales. In addition, the corrected item total correlations of each subscale were examined to determine the correlations between the subscales and their items. Pearson's correlation coefficients and paired samples t-test were used to investigate the consistency between the assessments of mothers and children for the PODCI and PedsQL scales which were completed by both mother and child samples.

Independent samples t-test was used to assess the criterion

validity of the scales which indicates their strength in discriminating healthy and cerebral palsied groups. Additionally, a t-test was also conducted to assess the ability of the scales to discriminate between the groups with CP in terms of the GMFCS levels. Non-parametric tests were used as the number of children in the subgroups of GMFCS levels and age was not similar. Thus, the Kruskal Wallis test was used to specify the discrimination of the scale scores in accordance with the GMFCS and age subgroups and the Mann Whitney U tests were then used to identify the cause of the observed significant effects.

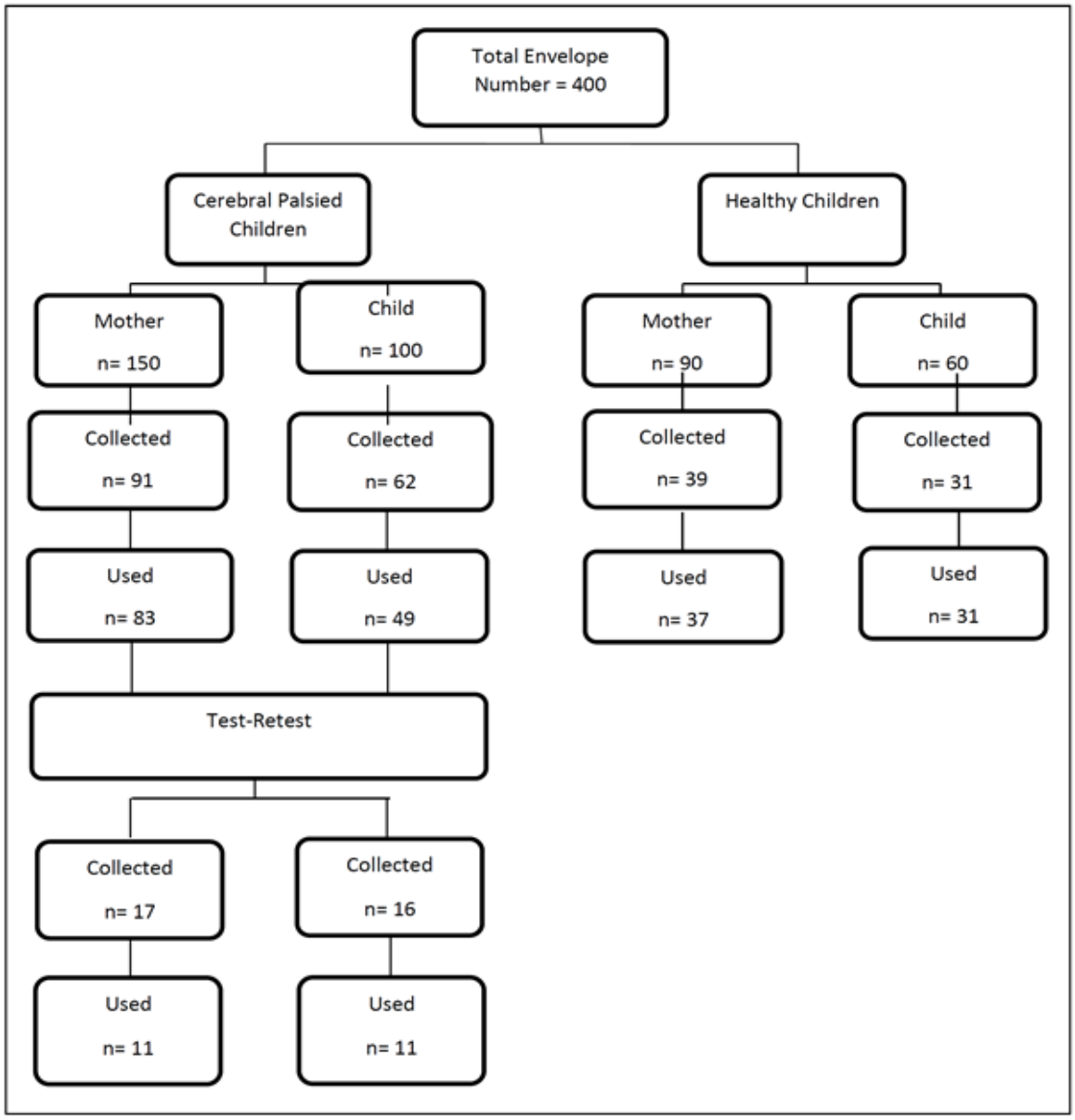
Statistical power analysis was conducted to acquire statistical power at a medium level (80%). Power analyses showed that at the significance level of 0.05, minimum 15 participants were required for reliability analyses and a minimum of 45 participants were required for validity analyses. Correlations among subscales in mother and child samples were calculated to observe the convergent and divergent validity of the PODCI, the PedsQL and CHQ PF-50 scales. In terms of convergent validity, strong conceptual correlation between subscales found in the same group was expected, whereas weak correlation or no correlation between subscales measuring different features was expected according to the divergent validity.

RESULTS

Demographic and Socioeconomic Findings

In our sample; 20% of the children with CP were 2-7 years, 44% of them were 8-12 years, and 36% of them were 13-18 years old. 33% of the healthy children were 2-7 years, 23% of them were 8-12 years, and 44% were 13-18 years old. Observing all sample, 61% of the children were boys. In terms of the GMFCS groups in the study, the first group comprised children with level I *(%14, n=15)* and level II *(%34, n=36)*, the second group comprised children with level III *(%24, n=25)* and the third group comprised level IV *(%22, n=23)* and level V *(%6, n=6)*. The Chi square test showed that the distribution of the children with different age groups in different genders and socioeconomic levels was homogenic. *(Gender; χ^2 (2 =2.158, p=0.340, marital status; χ^2 (4) =1.96, p=0.743, education of mother; χ^2 (6) =1.897, p=0.929, occupation; χ^2 (10)=15.35, p=0.121, monthly income; χ^2 (6)=4.771, p=0.573)*

Figure 1: Flow chart of participants through the study



2. Findings related to the Pediatric Outcomes Data Collection Instrument (PODCI)

2.1 Reliability of the PODCI

Findings related to the reliability of the PODCI was presented in Table 1. As seen in Table 1, the coefficient of the internal consistency was at an acceptable level in all samples consisting of children and their mothers(*α=0.72 –0.96)*. In child sample, the internal consistency of the Pain/comfort (PC) subscale was just below the acceptable level (*α=0.66*), whereas the internal consistency of the Transfer and Basic Mobility (TBM) subscale was found to be above the acceptable levels (*α=0.96*). The test-retest reliability of subscales were at a significant levelfor all sample *(ICC=0.823 -0.999, r= 0.917 - 0.999; p<0.001)*.

The scores gathered from the children with CP and their mothers were examined in terms of children's age and age was found to have a significant effect on the ratings of the Upper Extremity and Physical Function (UEP), TBM, and Global Function and Comfort (GFC) subscales in the mother sample and of the UEP, SPF, TBM, and GFC subscales in the child sample (*for the mother sample; F(2,78)=7.18, F(2,80)=7.20, F(2,77)=6.30, p<0.05, respectively and for the child sample; χ2(48)= 168.5, χ2(48)=155, χ2(48)=136.5, χ2(48)=148, p<0.001, respectively)*. Comparing the means, it wasfoundthat 13-18 year-oldchildren had significantlyhigherscoresthantheotheragegroups. There was no significant difference among the age groups in the healthy sample. Inthechildsample, 13-18 year-oldchildren significantly differed from the other age groups (*χ2*(30)=59, p<0.05).

Table1: Finding related to the reliability of PODCI.

PODCI	Item number	Mother Sample			Child Sample			All Sample			Mother-Child Correlation (n = 27)
		Alpha (n = 83)	r (n = 11)	ICC	Alpha (n = 49)	r (n = 11)	ICC	Alpha (n = 132)	r (n = 22)	ICC	
GFC	4	.82	.999***	.990	.78	.999***	.995	.83	.999***	.993	.832***
UEP	8	.90	.999***	.985	.86	.999***	.990	.90	.982***	.988	.673***
SPF	12	.93	.987***	.968	.91	.985***	.990	.92	.904***	.974	.801***
TBM	11	.96	.999***	.999	.96	.999***	.990	.96	.999***	.999	.894***
PC	3	.77	.987***	.977	.66	.998***	.990	.73	.987***	.981	.584**
HAP	5	.72	.987***	.974	.80	.984***	.990	.75	.982***	.977	.583**
ET	10	.79	.917***	.823	.79	.995***	.990	.75	.971***	.957	.320

* p<.05, ** p<.01, *** p<.001

Examining the corrected item total correlation for the PODCI, the scale items generally showed strong correlation with the related subscales (for the mother, child and all sample; *r=0.269-0.909, r=0.331-0.895 and r=0.327-0.910,* respectively).

The consistency between the ratings of mothers and their children were found to be strong and significant in all subscales except the Expectations for Treatment (ET) subscale (*r=.320, p>.05*). There was a significant difference between the ratings of mothers and their children on the Sports and Physical Function (SPF) subscale, and the difference was marginally significant on TBM and Happiness/Satisfaction (HAP) subscales*(t(26)= -2.259, p<0.05, t(26)= -1.853, p=0.075 and t(26)= -1.950, p=0.062, respectively)*.

2.2 Validity of the PODCI

The mother sample, child sample and all sample obtained significantly higher scores than the healthy group did. PODCI was found to be successful in differentiating children with CP from healthy children *(p<0.001)*.

Analysing the scores of the PODCI subscales in terms of the GMFCS groups, the functional levels of groups were found to be parallel to the UEP, SPF and TBM subscales related to physical functioning (for the mother sample*; F(2,78)=31.70, F(2,78)=60.89, F(2,80)=63.23, p<0.001, respectively* and for the child sample*; F(2,45)=14.38, F(2,45)= 23.52, F(2,45)= 29.80, p<0.001, respectively)*.

3. Findings related to the PedsQL

3.1 Reliability of the PedsQL

As seen in Table 2, the internal consistency of the subscales of PedsQL except the Emotional Functioning (EF) subscale was at an acceptable level *(α= 0.71 - 0.88)*and test-retest correlations in all samples was found to be quite strong (*ICC=0.929 - 0.992,Pearson r=0.934 -0.999, p<0.001*).

The correlations between the PedsQL's items and the related subscales were generally at a medium level *(for the mother, child, and all sample r= 0.290-0.727, r=0.327-0.729*

and r=0.227-0.768, respectively). There were high and significant correlations in the consistency between the ratings of mothers and children except the EF (r=0.155, p>.05) and the Social Functioning (SF) subscales (r=0.282, p>0.05).

Table 2: Finding related to the reliability of thePedsQL

PedsQL	Item number	Mother Sample			Child Sample			All Sample			Mother-Child Correlation
		Alpha (n = 83)	r (n = 11)	ICC	Alpha (n = 49)	r (n = 11)	ICC	Alpha (n = 132)	r (n = 22)	ICC	
PHTS	23	.82	.934***	.929	.88	.990***	.972	.85	.966***	.955	.494**
EF	8	.83	.943***	.939	.85	.964***	.962	.86	.966***	.959	.502**
SF	5	.56	.956***	.935	.57	.965***	.966	.56	.955***	.956	.155
SchF	5	.71	.980***	.964	.76	.988***	.989	.72	.987***	.982	.282
PC	5	.74	.991***	.986	.68	.985***	.977	.72	.987***	.980	.719***
PSHTS	15	.81	.962***	.957	.82	.999***	.992	.81	.987***	.979	.607**

* p<.05, ** p<.01, *** p<.001

3.2. Validity of the PedsQL

The scores of the healthy and cerebral palsied groups were compared. The mother sample, child sample, and all sample in the healthy group were statistically significant and higher scores than the CP group so PedsQL was also found to be successful in differentiating children with CP from healthy children *(p<0.001)*.

The scores gathered from the children with CP and their mothers were examined in terms of the differentiation in the children's age groups and age groups affected significantly the ratings on the Physical Health Total Score (PHTS) subscale which is related to physical functioning-for the child sample (χ^2 (48)= 145, p<0.001), whereas it was affected marginally for the mother sample, but not significantly (F(2,80)=5.77, p=0.056). Moreover, children's age groups had significant effects on the total score of the PedsQL*(χ 2 (48)=114, p<0.001).* The differences between means indicated that the children in the age group of 13-18 years perceived themselves significantly healthier than those in the age group of 8-12 years.There was no significant differentiation between the age groups in the healthy sample.

The ability of the PedsQL to differentiate the scores of the children with CP according to their GMFCS levels was also examined and the functioning levels of the GMFCS groups were found to be parallel to the PHTS. Additionally, the total PedsQL scores of mothers and children were found parallel to each other (the PHTS subscale; F(2,80)=44.18, PedsQL total score; F(2,80)=14.15, p<0.001 in the mother sample and the PHTS subscale; F(2,45)=20.34, the PedsQL total score; F(2,45)= 8.90, p<0.001 in the child sample).

4. Findings related to the CHQ PF-50

4.1. CHQ PF-50's Reliability

The internal consistency of the CHQ PF-50 subscales, except the Behavior (BE) subscale *(α=0.55)* and the General Health perception (GH) subscale *(α=0.66),* was at an acceptable level. The Cronbach alpha coefficients of the Global Health (GGH), Global Behavior (GBE), and Family Cohesion (FC) subscales cannot be calculated since they consist of only one item. The findings related to the time consistency of the subscales presented that all subscales, except the Role/social limitations-Physical (RP) subscale, had significant test-retest correlations (ICC= 0.744-0.999, r=0.737-0.999, p<0.01).

The corrected item total correlations of each subscale were examined to investigate the internal consistency of the CHQ PF-50 and the scale items showed medium level correlations with their subscales (r=0.227 - 0.878) (Table 3).

Table 3: Findings obtained from the mother sample related to the reliability of CHQ PF-50.

	Item Number	Alpha (n = 74)	SFF	r (n = 11)	ICC
GGH	1	-	.989	.989***	.999
PF	6	.93		.962***	.952
REB	3	.89	-	.956***	.941
RP	2	.78	.863**	.442	.341
BP	2	.92	.370**	.943***	.930
BE	5	.55	.325**	.828***	.819
GBE	1	-	-.291**	.926***	.920
MH	5	.79		.892***	.815
SE	6	.70	.804**	.985***	.974
GH	5	.66	.059	.986***	.971
PE	3	.70	.153	.737**	.744
PT	3	.80	.105	.978***	.964
FA	6	.80	.145	.992***	.990
FC	1	-		.999***	.999

* p<.05, ** p<.01, *** p<.001

4.2. CHQ PF-50's Validity

Mothers of healthy children were found to make more positive assessments than the mothers of the children with CP *(p<0.001)*. Furthermore, like the other scales, CHQ PF-50 was successful in differentiating healthy samples from cerebral palsied samples.

In terms of the differentiation of the scores, there was a weak but meaningful effect of the age groups on the subscales Physical Function (PF), Role/social limitations – Emotional/Behavioral (REB), and GH ($F(2,71)=6.43$, $F(2,71)= 6.45$, $F(2,71)=7.78$; $p<0.05$, respectively). The differences among the means showed that the three groups differed significantly from each other. The first group had the highest mean (X =50.18) and the second and third groups followed that group with the means (X =22.98) and (X =5.05), respectively. Moreover, the GMFCS groups had significant effects on the subscales of the CHQ PF-50 which are related to physical functioning and health perception. Thus, criterion validity was ensured for these subscales.

5. Findings related to the convergent and divergent validity of the scales;PODCI, PedsQL and CHQ PF-50

Investigating the convergent validity for the mother sample; the UEP, SPF, TBM, PC subscales of the PODCI; the PHTS subscale of the PedsQL, and the PF, RP, Bodily Pain/Discomfort (BP) and GH subscales of the CHQ PF-50 which were related to physical functioning and pain had strong correlations with each other (r=0.311 - 0.863, p<0.01) (Table 4).

Table 4: Subscales correlations - Mother

	PODCI							PedsQL					
	GFC	UEP	SFF	TBM	PC	HAP	ET	TOP	PHTS	EF	SF	SchF	PSTS
PODCI													
GFC	-												
UEP	.829**	-											
SPF	.871**	.570**	-										
TBM	.941**	.758**	.863**	-									
PC	.604**	.311**	.370**	.345**	-								
HAP	.335**	.226*	.325**	.234*	.346**	-							
ET	-.291**	-.109	-.291**	-.241*	-.321**	-.129	-						
PedsQL													
TOP	.574**	.336**	.569**	.479**	.474**	.535**	-.390**	-					
PHTS	.798**	.564**	.804**	.746**	.383**	.309**	-.284**	.712**	-				
EF	.104	-.015	.059	-.009	.308**	.296**	-.462**	.581**	.195	-			
SF	.142	.093	.153	.115	.199	.435**	-.125	.671**	.153	.320**	-		
SchF	.069	-.145	.105	-.021	.320**	.433**	-.250*	.624**	.109	.355**	.355**	-	
PSTS	.150	.002	.145	.064	.359**	.504**	-.333**	.828**	.201	.684**	.803**	.756**	-
CHQ PF-50													
GGH	.417**	.355**	.405**	.364**	.243*	.312**	-.139	.447**	.411**	.043	.268*	.361**	.301**
PF	.791**	.610**	.851**	.774**	.322**	.331**	-.196	.507**	.738**	.037	.109	.142	.129
REB	.212	.166	.144	.073	.372**	.287*	.001	.386**	.147	.269*	.350**	.362**	.423**
RP	.552**	.430**	.633**	.464**	.286*	.382**	-.047	.465**	.489**	.127	.234*	.231	.268*
BP	.528**	.294*	.407**	.356**	.766**	.327**	-.292*	.502**	.430**	.365**	.200	.278*	.359**
BE	.127	.052	.089	.023	.305**	.283*	-.177	.487**	.129	.353**	.473**	.493**	.571**
GBE	.180	.144	.155	.104	.215	.267*	-.054	.405**	.197	.199	.421**	.320**	.410**
MH	.294*	.137	.298**	.154	.440**	.486**	-.367**	.615**	.323**	.576**	.389**	.467**	.602**
SE	.375**	.227	.370**	.249*	.437**	.464**	-.094	.451**	.297*	.202	.383**	.278*	.390**
GH	.481**	.353**	.442**	.424**	.374**	.232*	-.216	.448**	.493**	.153	.180	.206	.238*
PE	.320**	.271*	.215	.204	.404**	.366**	-.050	.533**	.359**	.274*	.407**	.397**	.459**
PT	.416**	.255*	.401**	.356**	.375**	.286*	-.322**	.499**	.395**	.331**	.294*	.288*	.390**
FA	.270*	.053	.358**	.167	.361**	.300**	-.303**	.512**	.271*	.413**	.454**	.288*	.502**
FC	.176	.096	.137	.074	.323**	.091	-.041	.213	.142	.226	.124	.145	.199

	CHQ PF-50													
	GGH	PF	REB	RP	BP	BE	GBE	MH	SE	GH	PE	PT	FA	FC
CHQ PF-50														
GGH	-													
PF	.404**	-												
REB	.133	.261*	-											
RP	.342**	.747**	.450**	-										
BP	.246*	.340**	.418**	.311**	-									
BE	.168	.199	.398**	.309**	.206	-								
GBE	.246*	.113	.350**	.213	.139	.667**	-							
MH	.210	.254*	.373**	.327**	.483**	.632**	.451**	-						
SE	.346**	.277*	.241*	.298**	.324**	.332**	.263*	.280*	-					
GH	.586**	.384**	.120	.320**	.327**	.257*	.314**	.294*	.355**	-				
PE	.417**	.311**	.377**	.439**	.349**	.609**	.458**	.452**	.212	.489**	-			
PT	.243*	.499**	.282*	.484**	.257*	.523**	.341**	.478**	.274*	.347**	.621**	-		
FA	.262*	.302**	.242*	.373**	.356**	.289*	.167	.482**	.400**	.194	.305**	.526**	-	
FC	.144	.055	.092	.168	.224	.182	.259*	.181	.235*	.151	.193	.119	.300**	-

* p<.05, ** p<.01, *** p<.001

The HAP subscale of the PODCI, the EF subscale of the PedsQL, and the MH and SE subscales of the CHQ PF-50 which were related to emotional functioning also had strong correlations with each other (r= 0.260 –0. 575, p<0.05). Moreover, the correlations among the subscales related to social functioning were found to be strong. Thus, convergent validity for the mother sample was supported.

Examining the divergent validity for the mother sample; the correlations between the subscales related to physical functioning, pain and the subscales related to emotional functioning, particularly those of the CHQ PF-50 scale, were found to be relatively strong (*r=0.294 – 0.440, p<0.05).* In addition, the correlation between the physical and emotional functioning subscales within the PODCI and CHQ PF-50 was also quite strong (PODCI r=0.226 – 0. 346, CHQ PF-50 r=0.254 – 0.483, p<.05). On the other hand, the correlation between the PHTS and EF subscales in the PedsQL was not significant so the divergent validity of this scale for these subscales was shown. In terms of the findings related to the social functioning, there was no significant correlation between the SF, School Functioning (SchF) subscales of the PedsQL and all physical subscales (r<0.231, p>0.05) and the social functioning subscales of the CHQ PF-50 with the subscales of the PODCI related to physical functioning (r<0.215, p>0.05). Only the PF subscale of the CHQ PF-50 which was related to physical functioning separated from the subscales related to social functioning. Moreover, the correlations between the subscales of the CHQ PF-50 related to physical and social functioning were found to be strong (r=0.257-0.450, p<.05). There were strong correlations between the subscales when the differentiation of the subscales related to emotional and social functioning was analyzed (r=0.241-0.632, p<0.05).

Examining the scores of the child sample (Table 5) to identify the convergent validity, strong and significant correlations were observed among the UEP, SPF and TBM subscales of the PODCI and the PHTS subscale of the PedsQL(r=0.412-0.801, p<0.01). However, no significant correlation was shown between the PC subscale and the other PODCI subscales (r<0.28. p>0.05). These findings indicate that convergent validity was supported for all subscales, except the PC subscale. The correlation between the HAP and EF subscales related to emotional functioning was also quite strong (r=0.495, p<0.01). Finally, there was a strong correlation between the SF and SchF subscales related to social functioning (r=0.443, p<0.01).

Table 5: Subscales correlations - Child

	PODCI					PedsQL							
	GFC	UEP	SPF	TBM	PC	HAP	ET	TOTAL	PHTS	EF	SF	SchF	PSTS
PODCI													
GFC	-												
UEP	.801**	-											
SPF	.881**	.559**	-										
TBM	.900**	.766**	.801**	-									
PC	.469**	.148	.280	.118	-								
HAP	.262	.033	.280	.068	.458**	-							
ET	-.216	-.183	-.230	-.176	-.068	-.065	-						
PedsQL													
TOTAL	.562**	.312*	.634**	.347*	.444**	.524**	-.252	-					
PHTS	.801**	.581**	.784**	.666**	.412**	.329*	-.357*	.835**	-				
EF	.240	.007	.330*	.009	.424**	.495**	.018	.689**	.355*	-			
SF	.149	.005	.304*	-.051	.221	.511**	-.066	.757**	.411**	.550**	-		
SchF	.182	.015	.235	.060	.260	.327*	-.225	.715**	.441**	.432**	.443**	-	
PSTS	.234	.021	.359*	.004	.363*	.558**	-.101	.893**	.500**	.797**	.856**	.767**	-

* p<.05, ** p<.01, *** p<.001

Analyzing the scores of the child sample to identify the divergent validity, the HAP and EF subscales related to emotional functioning were separated from the subscales related to physical functioning, except the PC (r<0.330 p≥0.05). No significant correlation between the SF and SchF subscales related to social functioning and the subscales of the PODCI related to physical functioning was observed (r<0.26 p>0.05). There was only one correlation between the SPF and SF subscales and it was weak but significant (r=0.33. p<0.05). However, the SF and SchF had quite strong correlation with the PHTS subscale (r=0.411, p<.01 and r=0.441, p<0.01, respectively). Strong and significant correlations between the subscales related to emotional and social functioning were observed (r=0.327-0.550, p<0.05).

DISCUSSION

The purpose of our study was to determine the reliability, validity, and sensitivity of the Turkish versions of three scales and to get usage of them more common for CP population. Assessment of the functional health status and the HRQOL ofthe children with CP are essential to specify the needs of parent and child, to focus on solutions and to acquire an effective rehabilitation content. Therefore, this study investigated whether the Turkish versions of the PODCI, PedsQL and CHQ PF-50 scales were reliable, valid, and sensitive in children with CP who were involved in different age groups and impairment levels.

The recruited children were distributed into three age groups, because maturing changes expectations and social roles. Obtaining information from the children with CP is important to understand their problems as felt or perceived by themselves so the children who were found in the 10-18 age group were assessed by their feedback [20]. With this aspect, this study is the first in Turkey for the children with CP.

Previous papers showed the reliability and validity of the scales PODCI, PedsQL and CHQ PF-50 for the children with CP in their developed languages[9, 11, 21]. In Turkey, Üneri (2007), [22] indicated the reliability and validity of the 2-7 age child form of the PedsQL for the children with CP. In addition, in a study by ÇakınMemik et al. (2008) [23, 24], the reliability and validity of both 8-12 age child and 13-18 age adolescent forms of the PedsQL for acute and chronic diseases were proven. Furthermore, Özdoğan et al. (2001) [19] showed that the CHQ PF-50 was reliable and valid for the children with Juvenile Idiopathic Arthritis (JIA). The current study is important in investigating the reliability, validity, and sensitivity of these three scales, increasing their use in clinics and supplying reference to develop new scales.

1. Reliability of the scales PODCI, PedsQL and CHQ PF-50

The PODCI scale indicating an internal consistency at an acceptable level had parallel findings with the reliability and validity studies in its original language so the UEP, TBM, SPF subscales had internal consistency at an acceptable level, while the pain subscale had a relatively lower level of internal consistency [11]. The findings revealed that the TBM subscale had a significant internal consistency which could be associated with the way of its assessment as its items examine transfer and mobility with a similar level of difficulty and thus similar answers were obtained.

Similar to our finding, Park et al. (2012) [25] also investigated the acceptability of the PODCI for various assessments and revealed that the SPF subscale was successful in measuring the function in CP. Since the number of the total items of the pain subscale is less than in the other subscales, increasing the items in pain subscale could increase its internal consistency.

Daltroy et al. (1998) [12] reported that the ET subscale was not included in some analyses because of lots of missing data and this situation was explained with limited expectations of the parents. In this study, this subscale had nearly no missing data and while item 82 of the PODCI (I expect to be able to do more at school) showed a weak correlation, no correlation was indicated for item 85 (I expect to be free from pain or disability as an adult). This result showed that the mothers who have a low or medium level of education had similar and high expectations for their children in various functional levels. When these high expectations are not met, mothers and children may face problems so a family education about the therapy and rehabilitation of CP would be beneficial.

The SPF subscale had no significant correlation in child sample and in all sample so a change in the statement of item 60 (How often in the last week did your child get together and do things with friends?), giving examples for the activity conception, and increasing the option number may increase the correlation.

In general, PedsQL performed internal consistency at an acceptable level. Nevertheless, internal consistency of the EF subscale for mother, child and all sample and the SchF subscale for child sample was lower than acceptable limits. These findings were similar to results obtained from the studies by Memik et al. and Daltroy et al. [11, 23, 24]. In addition, Varni et al. (2005) examined the reliability and validity of the PedsQL scale in children with CP and reported similar internal consistency (α=0.79-0.91) of its subscales to the current paper [26].

Observing the item total correlations, there was no significant correlation in the SchF subscale of the child sample with item 4 (I miss school because of not feeling well) and item 5 (I miss school to go to the doctor or hospital). Acquiring similar findings to the previous studies indicates that changing items is necessary [23, 24]. The internal consistency of the EF subscale was found to be weak for each sample in this paper, whereas its items 3. (I feel angry) and 4. (I have trouble sleeping), had a weak but significant correlation in the previous papers [23, 24].

This paper revealed that the CHQ PF-50 scale generally had an internal consistency at an acceptable level and the internal consistency levels of the behavior and the perception of general health subscales were lower than the acceptable limits. Similarly, McCullough et al. (2009) [20] stated that the CHQ PF-50 in CP population had limited applicability. They also reported that there were ceiling effects in various subscales and a floor effect in the "physical functioning" subscales [20]. The variety of the problems seen in the children with CP as well as parents' ambitiousness to show their children as healthy to peers could cause these ceiling and floor effects. Thus, the CHQ PF-50 was not sensitive to differentiate the numerous types of children with CP. As a result, although McCullough et al. found the reliability findings satisfied, the internal consistency of the "behavior", "general health", and "mental health" subscales was not adequate (α<0.7). Similar results related to these three subscales were also obtained from the study by Morales et al. [27].

The Turkish version of the CHQ PF-50 scale was used for the parents of 85 children with JIA and similar to all findings, the internal consistency of the behavior subscale was found to be weak [19] . Examining the item total correlations of this subscale, item 5.1.c (lie or deceive) showed no significant correlation and the correlation of item 5.1.d (steal anything indoors or outdoors) was r=0.000 because no mother would report that her child steals. Stealing is an extreme behavior so softer statements like "taking without permission" should be used to increase the variance in the answers of this item and solve the problem. According to the item total correlations of the perception of general health, item 8.1.c (If there is ..... my child usually gets it) showed a weak but significant correlation. The similar answers of the mothers to this item or having weak correlation with other items could cause this finding.

Although the internal consistency of the self-respect subscale was found at an acceptable level, item 7.1.e (How happy is your child with the "family relationships") had a weak but significant correlation in the item total correlations. This is because mothers refused to state their relationships negatively and also they are usually not aware of their child's thoughts about this. According to the results of the analysis, the findings acquired from the CHQ PF-50 items related to family relationships and adjustments may not be reliable due to the cultural differences in Turkey. Eleven children and their mothers completed the scales two times after three days from the first time to investigate the consistency in time. Three days were found to be an appropriate duration for the second time of retesting as longer duration could lead to changes in the situation of child and when using a shorter duration, children and mothers might remember the items too easily. The findings showed that the test-retest reliabilities of the subscales of the PODCI and PedsQL were quite high. Similarly, the test-retest reliability of the PODCI was indicated in the previous studies, whereas no study has investigated it for the PedsQL [11, 23, 24]. This reliability for the CHQ PF-50 had significant correlations in all subscales except the subscale role/social limitations due to the physical health which could not be understood by the participants. On the other hand, Ozdogan et al. (2001) applied the CHQ PF-50 two times with a long duration time interval, 7 to 65 days, to search the test-retest reliability of its Turkish versions and they revealed weak time consistency [19] .

The consistency of mothers and children scores in the PODCI and PedsQL scales showed that the scores from the

physical functioning subscale were correlated, while the scores from the emotional and social functioning subscales differ. Similarly, previous studies showed that mother-child correlation was strong in the physical function domain, but there was a weak or no correlation in the answers of mothers and children about satisfaction and expectations [11, 21, 28-30]. Two studies among them explained this situation in that that mothers usually tend to focus on the things which their child could not do, whereas children tend to show their skills [11, 30].

Haynes and Sullivan (2001) involved 27 pairs of children and mothers for the PODCI and indicated no significant difference in any subscale between mothers and children [29]. Opposite to this study, Eiser and Morse (2001) stated that child and parent had different health-disease perception and different experiences in various situations so it seemed not possible to observe a similarity in the assessments of child and parents [10]. In addition, parents assessed their child in objective areas better than in subjective areas and also mother-child differentiation changed according to the preferred subscales [10, 31, 32].

As a result, there was a significant difference in the physical function subscale and satisfaction and expectations, whereas the children had higher means of the subscales, but the only significant difference was found in the physical function subscale. In literature, it was shown that if any of the parents of children is present while children complete the scales, this affects their answers and also no significant differences are acquired in the areas related to sociality [32]. Thus, the results of this study could be affected as it was not always possible to ensure the children complete the scales alone and moreover, as a limitation of the paper, there was no adequate mother-child pair (n=27).

2. Validity of the scales PODCI, PedsQLve CHQ PF-50

The PODCI means of the healthy sample in the study showed parallel findings with the PODCI assessments of healthy adolescents and their parent in the study by Haynes and Sullivan [29]. All children with CP assessed all subscales of the three scales more negatively than the healthy children did. According to the findings of the validity of the PODCI, PedsQL and CHQ PF-50, these three scales were successful in differentiating the CP and healthy samples from each other. This result was also supported in various papers [23, 24, 26, 33]. Moreover, the children with CP had lower scores in functional health status and the HRQOL scales than the healthy children so this revealed that CP negatively affects the functional health status and the HRQOL of children.

The differentiation of the scores according to the age groups of the involved children showed that the 13-18 age group had better scores in the subscale related to physical functioning than other age groups. The children in the 13-18 age group were mostly in GMFCS levels I and II so this can cause their significantly higher scores in the mentioned subscale. Similarly, Daltroy et al. observed that the physical functioning scores in the PODCI scale increased with age and explained that younger aged children with CP had more severe impairments and a lower functional level [11].

When the differentiation of the scores according to the age groups of the healthy sample was examined, the 13-18 age group showed themselves significantly better than the 8-12 age group according to the PODCI scale. The differentiation among the healthy children may result from the focus of physical development on sport activities, but this statistically significant finding does not seem to be an essential clinical implication.

It was expected to acquire differentiation in the physical functioning domain of the HRQOL scale between the groups of the GMFCS which classifies children according to their normal motor development, transfer and walking aids [34]. Thus, the subscales related to physical functioning of all three scales had statistically significant differences in the GMFCS groups so the scales were successful in discriminating among the children in terms of the GMFCS levels and various papers confirmed this information [22, 28, 35, 36]. Furthermore, the criteria validity was only provided for the subscales related to physical functioning and pain so a different criteria is required to investigate the validity of the social, emotional and family subscales in further studies.

3. Relationship between the scales PODCI, PedsQLve CHQ PF-50

The assessment method of the PODCI is similar to the PedsQL's because both of them have different versions for different age groups (e.g. child and adolescent form) and also for mothers and children. Thus, these two scales provide a measurement of the HRQOL of children using the views of both mothers and children. Moreover, both scales have simple language and include the questions about physical functioning, emotional functioning and pain. Despite these similarities of the PedsQL and PODCI, there are more items in the PODCI than items in the PedsQL as the PODCI presents more detailed information about physical functioning and pain than the PedsQL and also, the PODCI allows to determine the expectations of mothers and children from the treatment. In addition, the PedsQL investigates social and school functioning in different subscales which is the other differing content from the PODCI. The reliability and criterion validity of these scales used had similar values in the study.

The CHQ-PF 50 and the PODCI have similar age intervals and both of them present detailed information. The questions about physical functioning, emotional functioning and pain are found in both scales. On the other hand, the PODCI provides more detailed information about pain and physical functioning, and allows assessing the expectations of mothers and children from the treatment which is not a subscale in the CHQ PF-50. However, the effects of physical and emotional status on the role and social status of child, the influences of disease on family and adaptation to disease were differently examined in the CHQ PF-50 from the PODCI. The reliability and criterion validity of

these two scales had similar values in the study.

The conceptual correlations of the subscales of the PODCI, PedsQL and CHQ PF-50 with each other had convergent validity, but no divergent validity was found. The subscales examined had the items which could be correlated ("how happy have you been with your athletic skills?" found in the emotional functioning and social functioning subscale or "how happy have you been with your ability to do the same things your friends do?" found in the physical functioning subscale) so different areas like emotions, social skill and physical skills of the children with CP could not be assessed independently and this led to no divergent validity. In consequence, the PODCI, PedsQL and CHQ PF-50 were valid and reliable scales which could specify the functional health status and the HRQOL of the children with CP. The PODCI presents comprehensive data about physical functioning and participation (functions of upper limb, transfer basic mobility, sport and physical function). While analyzing emotional functioning, important information is obtained about the expectations of children and parents from the treatment. Despite its comprehensive structure, it is easy to use with its plain language and it can be used in a wide age interval. Thus, among these three scales, PODCI seems more practical in examining functional health status of the children with CP. The content of the PedsQL is narrow as pain is questioned with one item and physical functioning is examined in one extent so it does not present adequate information. On the other hand, various authors preferred it because it has both child and adolescent versions and it is easy to use [18, 37, 38]. Although the CHQ PF-50 did not have the Turkish version of child form which allows a comparison between the answers of children and parents to similar questions, it can be preferred to obtain information about family activities, family adjustment and the influences of the disease on the parent [19, 38].

Study Limitations

As mentioned in the discussion section, the mothers were sometimes next to their children while the children were filling in the forms and this could affect the children's answers. Furthermore, a larger number of mother-child pairs for the test-retest could provide more data.

Conclusion

Lastly, in Turkey, it is essential to provide a widespread use of the scales like the PODCI, PedsQL and CHQ PF-50 to determine the expectations of the children with CP who are a sizeable population and to decide the areas which they need support. This study revealed that these scales are reliable and valid so it is considered that their use in clinics will be practical.

List of Abbreviations:

BE = Behavior
BP = Bodily Pain/Discomfort
CHQ PF-50 = Child Health Questionnaire Parent Form
CP = Cerebral Palsy
EF = Emotional Functioning
ET = Expectations for Treatment
FC = Family Cohesion
GBE = Global Behavior
GFC = Global Function and Comfort
GGH = Global Health
GH = General Health Perception
GMFCS = Gross Motor Function Classification System
HAP = Happiness
HRQOL = Health-related Quality of Life
LAQ = Lifestyle Assessment Questionnaire
PC = Painless/comfort
PedsQL = Pediatric Quality of Life Inventory
PHTS = Physical Health Total Score
PODCI = Pediatric Outcomes Data Collection Instrument
PSHTS = Psychosocial Health Total Score
REB = Role/social limitations-Emotional/Behavioral
RP = Role/social limitations-Physical
SchF = School Functioning
SF = Social Functioning
SPF = Sports and Physical Function
TBM = Transfer and Basic Mobility
UCPA = United Cerebral Palsy Association
UEP = Upper Extremity and Physical Function

Ethics, Consents and Permissions:

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards (Hacettepe University Ethical Committee, LUT 09/68).

Conflict of Interests

The authors declare that they have no conflict of interest.

Author's Contributions

NK, MKG and TA have made substantial contributions to conception, design, acquisition, analysis and interpretation of data andhave given final approval of the version to be published. ZG, EST, and ÖC have been involved in translating, drafting and revising the manuscript and they also contributed to interpretation. All authors agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. All authors declared that each author participated sufficiently in the work.

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