



# Validation of the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) in a sample of Turkish non-ambulatory children with cerebral palsy

Bakım Veren Öncelikleri ve Engelli Çocuk Yaşam Sağlık Endeksi (CPCHILD)'nin yürüyemeyen Türk beyin felçli çocuklarda geçerlilik ve güvenilirlik çalışması

<sup>1</sup> Tülay Tarsuslu Şimşek<sup>1</sup>, <sup>2</sup> Meral Sertel<sup>2</sup>, <sup>3</sup> Eylem Tütün Yümin<sup>3</sup>, <sup>4</sup> Bahar Aras<sup>4</sup>, <sup>5</sup> Unni G. Narayanan<sup>5</sup>

<sup>1</sup>School of Physical Therapy and Rehabilitation, Dokuz Eylül University, İzmir, Turkey

<sup>2</sup>Department of Physiotherapy and Rehabilitation, Kırıkkale University Faculty of Health Science, Kırıkkale, Turkey

<sup>3</sup>Department of Physiotherapy and Rehabilitation, Abant İzzet Baysal University Faculty of Health Science, Bolu, Turkey

<sup>4</sup>Department of Physiotherapy and Rehabilitation, Kütahya Health Science University Faculty of Health Science, Kütahya, Turkey

<sup>5</sup>Department of Surgery & Child Health Evaluative Sciences, Toronto University, Toronto, Kanada

**Cite this article as:** Tarsuslu Şimşek T, Sertel M, Tütün Yümin E, Aras B, Narayanan UG. Validation of the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) in a sample of Turkish non-ambulatory children with cerebral palsy. *Turk Pediatri Ars* 2019; 54(1): 13–27.

## Abstract

**Aim:** The aim of this study was to translate and transculturally adapt the Caregiver Priorities and Child Health Index of Life with Disabilities questionnaire into the Turkish language and test the reliability and validity.

**Material and Methods:** Eighty-two children with cerebral palsy and their parents were included in the study. The majority of children had spastic cerebral palsy. According to the Gross Motor Function Classification System, 26 children were level III, 30 children were level IV, and 26 children were level V. International accepted guidelines were used in the transcultural adaptation and validation process. Reliability was assessed through statistical analysis of the test results for test-retest and internal consistency. To assess construct validity, Caregiver Priorities and Child Health Index of Life with Disabilities was compared with the Child Health Questionnaire Parent Form. Concurrent validity was assessed by examining how Caregiver Priorities and Child Health Index of Life with Disabilities scores changed according to Gross Motor Function Classification System levels.

**Results:** The mean total score of Caregiver Priorities and Child Health Index of Life with Disabilities was 58.34±26.39. The intraclass correlation coefficient for the total questionnaire score was 0.75, ranging from 0.43 to 0.89 for six domains. Cronbach's alpha was above 0.80 in all domains of Caregiver Priorities and Child Health Index of Life with Disabilities, except the health domain. The construct validity was good because there was a positive correlation between total Child Health Questionnaire Parent Form and Caregiver Priorities and Child Health Index of Life with Disabilities scores ( $r=0.58$ ,  $p<0.01$ ) according to the Pearson correlation analysis. Caregiver Priorities and Child Health Index of Life with Disabilities scores were found to be different between Gross Motor Function Classification System levels ( $p<0.05$ ).

**Conclusion:** This study showed that the Caregiver Priorities and Child Health Index of Life with Disabilities appears to be easy to administer, seems to have significant validity and reliability, and may be useful in the evaluation of health-related quality of life of children with cerebral palsy.

**Keywords:** Cerebral palsy; Child Health Index of Life with Disabilities; health-related quality of life

## Öz

**Amaç:** Bu çalışmanın amacı, Bakım Veren Öncelikleri ve Engelli Çocuk Yaşam Sağlık Endeksi anketinin Türkçe'ye uyarlanması, geçerlilik ve güvenilirliğini çalışmaktır.

**Gereç ve Yöntemler:** Çalışmaya 82 beyin felçli çocuk ve ailesi alındı. Ayrıca çalışmaya alınan çocukların büyük çoğunluğu spastik tip beyin felci olup, 26'sı Kaba Motor Fonksiyon Sınıflama Sistemi'ne göre seviye III, 30'u seviye IV ve 26'sı seviye V idi. Öncelikle, Bakım Veren Öncelikleri ve Engelli Çocuk Yaşam Sağlık Endeksi'nin çeviri ve geri çeviri işlemi gerçekleştirildi. Güvenirlik, test-tekrar test ve iç tutarlılık ile değerlendirildi. Yapı geçerliliği, Çocuk Sağlığı Ebeveyn Formu ile değerlendirildi. Eşzamanlı geçerlilik ise çocukların Kaba Motor Fonksiyon Sınıflama Sistemi seviyeleriyle, engelli çocuk yaşam sağlık endeksi skorlarının nasıl değiştiğine bakılarak değerlendirildi.

**Bulgular:** Bakım Veren Öncelikleri ve Engelli Çocuk Yaşam Sağlık Endeksi için ortalama toplam skor 58,34±26,39 olarak belirlendi. Ölçeğin iç tutarlılık değeri her 6 alt ölçüm için 0,43 ile 0,89 arasında değişen değerlerde olup, toplam skor için 0,75 olarak saptandı. Cronbach alpha değeri sağlık alt başlığı hariç bütün alt ölçümlerde 0,80 değerinin üstünde bulundu. Yapı geçerliliği için yapılan Pearson korelasyon çözümlemesine göre Çocuk Sağlığı Ebeveyn Formu ile Bakım Veren Öncelikleri ve Engelli Çocuk Yaşam Sağlık Endeksi arasında pozitif yönde bir ilişki bulundu ( $r=0,58$ ,  $p<0,01$ ). Bakım Veren Öncelikleri ve Engelli Çocuk Yaşam Sağlık Endeksi skorları Kaba Motor Fonksiyon Sınıflama Sistemi seviyeleri arasında farklı bulundu ( $p<0,05$ ).

**Çıkarımlar:** Bu çalışma, Bakım Veren Öncelikleri ve Engelli Çocuk Yaşam Sağlık Ölçeği'nin beyin felçli çocuklarda sağlıklı ilişkiyi yaşam kalitesinin değerlendirilmesinde önemli derecede yararlı olduğunu, ölçeğin oldukça yüksek geçerlilik ve güvenilirliğe sahip olduğunu göstermiştir.

**Anahtar sözcükler:** Engelli Çocuk Yaşam Sağlık Endeksi, serebral palsi, yaşam kalitesi

**Corresponding Author / Sorumlu Yazar:** Tülay Tarsuslu Şimşek E-mail / E-posta: [tulay\\_tarsuslu@yahoo.com](mailto:tulay_tarsuslu@yahoo.com)

**Received / Geliş Tarihi:** 07.02.2018 **Accepted / Kabul Tarihi:** 15.01.2019

© Copyright 2019 by Turkish Pediatric Association - Available online at [www.turkpediatriarsivi.com](http://www.turkpediatriarsivi.com)

© Telif Hakkı 2019 Türk Pediatri Kurumu Derneği - Makale metnine [www.turkpediatriarsivi.com](http://www.turkpediatriarsivi.com) web adresinden ulaşılabilir.

DOI: 10.14744/TurkPediatriArs.2019.57778

## Introduction

Cerebral palsy (CP) is a disorder of movement, muscle tone, and posture development, which are attributed to non-progressive disturbances occurring in the developing brain (1). It is the most common developmental disability that restricts children's activity level and participation in daily life (1, 2). Although CP is a non-progressive disorder, the problems due to the symptoms can be progressive and this may increase the severity of the disability. Between 25–35% of children are severely affected and they exhibit various health problems. Children with severe CP also have difficulties in daily life activities (feeding, toilet, dressing), communication, and mobility (3). The children's independence and quality of life decrease when their performance in activities of daily living are reduced (4).

Quality of life (QoL) is defined as an individual's emotional, physical, and social well-being. It is the degree to which an individual's life satisfies that individual's goals, wants, expectations, and needs (5). In children with CP, the evaluation of functional status and quality of life are quite important for planning treatment and to evaluate its effectiveness. There are several generic and condition-specific QoL instruments available. Despite the availability of numerous pediatric QoL questionnaires, not all are suited to assess QoL in children with CP (6–8). The generic scales, which were used to evaluate the QoL of children with CP are not specific for neuromuscular diseases. These scales mostly focus on functioning rather than psychosocial well-being. On the other hand, the scales that are used for the evaluation of QoL in children are suitable for those with mild and moderate CP, but they are inappropriate for non-ambulatory children and severely affected children with CP because many of the items in these scales do not apply to children with a severe disability (6). These include the Child Health Questionnaire (CHQ) (9), the Pediatric Quality of Life Inventory™ (PedsQL™) (10) and the KIDSCREEN (11), and do not accurately measure the health-related QoL (HRQoL) of individuals with severe CP.

To address the lack of evaluation scales for severely affected children with CP, the condition-specific Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) questionnaire was developed to evaluate the HRQoL and well-being of these children (7). Unlike other questionnaires, CPOCHILD was specifically developed by taking into account the experiences of caregivers of children with severe CP as well as healthcare professionals who were responsible for the treatment of these children. The questionnaire was developed for the Canadian

population in English. In addition to this, Brazilian-Portuguese, Dutch, German and Korean translations have been developed and validated (3, 12–14).

The aim of this study was to translate and transculturally adapt the CPOCHILD questionnaire into Turkish, and to test the reliability, validity, and internal consistency of the Turkish version of the CPOCHILD. We planned this study because of the absence of a suitable scale in Turkish, resulting in a lack of evaluation of the HRQoL of children with severe CP in Turkey.

## Material and Methods

### Design

This study was conducted at five different special education and rehabilitation institutions enrolling children who were involved with rehabilitation programs. All procedures performed 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. This study was approved by the Abant İzzet Baysal University Clinical Research Ethics Committee. (13.04.2011/13). The parents/caregivers of the children included in the study signed a consent form in which the method and aim of the study was explained.

### Participants

Sample size recommendations for such a study is between 50–100 participants (13, 15). The two original validation studies of the CPOCHILD were conducted with 52 and 67 participants (7, 16). Other translation, cross-cultural adaptation, and validation studies were conducted with 30, 66, and 68 subjects (3, 13, 14). Eighty-two children with CP and their parents-caregivers were included in this study. Parents who were the primary caregivers of children with CP aged 5 to 18 years were included. The gross motor function of the children was classified using the Gross Motor Function Classification System (GMFCS) (17). The children who were at level III-V according to the GMFCS were included in the study. The clinical characteristics of the children and socio-demographic data of the caregivers were recorded.

### Procedure

#### Scales

The CPOCHILD, a condition-specific measure of health status and well-being of children with severe CP was developed specifically for this population. The CPOCHILD consists of 37 items distributed over six sections representing the following domains: (1) personal care, (2) po-

sitioning, transfer and mobility, (3) communication and social interaction, (4) comfort, emotions and behavior, (5) health, and (6) overall QoL. Each item is rated on a 6- or 7-point scale, and for some items, in addition, a 4-point level of assistance modifier. Transformed scores from 0 (worst) to 100 (best) are calculated for a total CPCHILD score, as well as for each of the six sub-scales or domains (7, 16) (Appendix 1, Turkish version of scale).

The Child Health Questionnaire Parent Form (CHQ PF-50) has 13 domains or subscale scores: physical functioning (PF), role limitations-emotional/behavioral (REB), role limitations-physical (RP), bodily pain (BP), behavior (BE), mental health (MH), self-esteem (SE), general health perceptions (GH), parental impact-emotional (PE), parental impact-time (PT), family activities (FA), family cohesion (FC) and change in health (GGH). The CHQ-PF50 also includes three item measures of global functioning. The CHQ-PF50 has been validated in several countries and languages and results consistently indicate that the measure is psychometrically sound (18). CHQ scores range from 0 to 100, with higher scores indicating better HRQoL. In this study, the Turkish version of CHQ-PF50 was used (19). We chose the CHQ-PF50 because it evaluates the QoL and well-being of children with disabilities including CP. It was culturally adapted for Turkish people and the measurement properties were tested.

#### *Translation and cross-cultural adaptation*

Permission for the adaptation of the questionnaire was obtained from the authors of the questionnaire before the study. We used the cross-cultural adaptation designs proposed by Guillemin et al. (20) and Ruperto et al. (21) during the translation process. Two forward translations were performed from English to Turkish by translators whose native language was Turkish. One of the translators was blinded to the purpose of the study and the concepts being examined in the questionnaire. The other translator, who was a professional experienced in treating children with disabilities, was given information about the purpose of the study and the concepts being quantified. The two translations provided two preliminary Turkish versions from both clinical and literal perspectives.

A meeting was held with the two translators and two other physiotherapists experienced in pediatric rehabilitation to compare the two versions. A consensus was reached, which was then back translated into English by two native English speakers who did not know the purpose of the study, but had acquired the necessary reading and writing skills in Turkish. Each of the two translations was then compared with the original version. A bilingual team consisting of the 4 translators and 2 physiothera-

pists involved in the first meeting reviewed the Turkish version of the questionnaire in order to make the cross-cultural equivalence and to achieve semantic, idiomatic, experimental, and conceptual equivalence. The adapted translation was then tested by means of one-to-one interviews with 20 parents of children with CP. None of the statements were changed or altered.

#### **Statistical Analysis**

##### *Assessment of reliability*

The test-retest reliability of CPCHILD was determined by using the intraclass correlation coefficient (ICC) including 95% confidence intervals (CI). The CPCHILD was administered to the parents/caregivers twice, separated by a 2-week interval. For the ICC, values were accepted as follows: between 0 and 0.20 was poor, 0.21 and 0.40 was fair, 0.41 and 0.60 was moderate, 0.61 and 0.80 was good, and between 0.81 and 1.00 was excellent reliability (22, 23). For the internal consistency of CPCHILD, Cronbach alpha ( $\alpha$ ) coefficients were calculated. Alpha coefficients between 0.70 and 0.95 for all domains were considered adequate; the value of alpha should be above 0.80 for acceptance as high internal consistency (23).

##### *Assessment of validity*

In order to assess construct validity, CPCHILD scores were compared with the Child Health Questionnaire Parent Form (CHQ PF-50). The relation between CPCHILD and CHQ PF-50 was investigated using Pearson correlation analysis. Construct validity coefficients were accepted as follows:  $r \geq 0.81$  to 1.0 as excellent, 0.61 to 0.80 as very good, 0.41 to 0.60 as good, 0.21 to 0.40 as fair, and 0 to 0.20 as poor validity (24). Concurrent validity was assessed by examining how CPCHILD scores changed according to GMFCS levels. Differences in the CPCHILD scores according to GMFCS levels were analyzed using ANOVA and the post-hoc Tukey test. We used parametric tests for the CPCHILD because the scores had near-normal distribution.

All statistical analyses were performed using the SPSS 20.0 for Windows software package. A probability value of  $p < 0.05$  was considered to indicate a significant effect.

#### **Results**

The mean age of children included in the study was  $11.04 \pm 5.26$  years. All of the parents participating in the study were mothers. The clinical characteristics of the children and demographic characteristics of both the children and caregivers are given in Table 1. The average time to complete the questionnaire was  $26.53 \pm 4.78$

**Table 1. Sociodemographic data of the participants**

	n	%
Data of children		
Age (X±SD, year)	11.04±5.26	
Height (X±SD, cm)	124.42±30.82	
Weight (X±SD, kg)	33.45±19.69	
Girl	39	47.6
Boy	43	52.4
Communication		
Yes	48	58.5
No	34	41.5
GMFCS		
Level 3	26	31.7
Level 4	30	36.6
Level 5	26	31.7
Spastic	62	75.6
Hypotonic	6	7.3
Dyskinetic	6	7.3
Ataxic	2	2.4
Mixed	3	3.7
Caregiver		
Data of mothers	82	100
Age (Mean±SD, year)	40.47±9.02	
Educational level		
Primary school	29	35.4
Secondary school	15	18.3
High school	24	29.3
University	8	9.8
None	6	7.3
Profession		
Housewife	75	91.4
Government employee	3	3.7
Worker	4	4.9

SD: Standard deviation; GMFCS: Gross Motor Function Classification System

(range, 20–40) minutes; individuals with lower educational levels required more time to complete the questionnaire. The mean (±SD) total score of the CPCHILD was 58.34±26.39.

#### Test-Retest Reliability & Internal Consistency

The ICC for the total questionnaire score was 0.75 and ranged from 0.43 to 0.89 for the six domain scores. There was no difference between the test-retest scores ( $p>0.05$ ). Cronbach's alpha for the total CPCHILD was 0.97 and was above 0.80 in all domains of the CPCHILD, except the health domain (Table 2). These results support good test-retest reliability and high internal consistency of the questionnaire.

#### Validity

According to the Pearson correlation analysis, there was a positive correlation between the total CHQ and CPCHILD scores ( $r=0.58$ ,  $p<0.01$ ). The relation between CHQ and CPCHILD domains is demonstrated in Table 3. This results showed that the construct validity of CPCHILD ranged between good and very good, except health domain, which had fair correlation ( $r=0.38$ ,  $p=0.01$ ).

In terms of concurrent validity, both total and domain scores of the CPCHILD, except the health domain ( $p>0.05$ ), were found to be significantly different between each GMFCS level ( $p<0.05$ ). Post-hoc test showed significant differences in CPCHILD scores between level III and IV, level IV and V, and level III and V of GMFCS ( $p<0.05$ , Table 4).

#### Discussion

The results of our study showed that the Turkish version of the CPCHILD had good reliability and validity for Turkish-speaking caregivers and could be used for the evaluation of the HRQoL of Turkish children with severe CP for clinical and research purposes.

**Table 2. Test-retest reliability of the CPCHILD domain scores and total score**

Domains CPCHILD (items)	ICC (95% CI)	Cronbach $\alpha$
Personal care and ADLs (9)	0.63 (0.55–0.63)	0.96
Positioning, transfer and mobility (8)	0.61 (0.45–0.68)	0.94
Communication and social interaction (7)	0.62 (0.55–0.70)	0.95
Comfort, emotions and behavior (9)	0.89 (0.65–0.98)	0.89
Health (3)	0.43 (0.02–0.50)	0.32
Overall quality of life (1)	0.64 (-0.46–0.79)	NA
Total score (36)	0.75 (0.60–0.84)	0.97

CPCHILD: Caregiver Priorities and Child Health Index of Life with disabilities; CI: Confidence intervals; ICC: Intraclass correlation; NA: Not applicable (Cronbach  $\alpha$  since only one item)



**Table 3. Pearson correlation coefficients between CPCHILD scores and CHQPF-50 total score**

CPCHILD scores	CHQPF-50	
	r	p
Personal care (8)	0.42	<0.001 <sup>a</sup>
Positioning, transfer and mobility (8)	0.52	<0.001
Communication and social interaction (7)	0.42	<0.001 <sup>a</sup>
Comfort, emotions and behavior (9)	0.62	<0.001 <sup>a</sup>
Health (3)	0.38	0.01 <sup>a</sup>
Overall quality of life (1)	0.45	<0.001 <sup>a</sup>
Total score	0.58	<0.001 <sup>a</sup>

CPCHILD: Caregiver Priorities and Child Health Index of Life with disabilities; Child Health Questionnaire- Parent Form; <sup>a</sup>p<0.05, Pearson correlation coefficients

The ICC score of the original validation study was 0.85, ranging between 0.59–0.87 for the domains (16). In the Dutch validation study, the ICC score was found as 0.73 for the total questionnaire and ranged between 0.55–0.80 for domains (13). The Turkish version of CPCHILD showed good test–retest reliability in the total ICC (0.75) and domain scores (ICC, 0.43–0.89) as similar to previous studies. In terms of internal consistency, Cronbach’s alpha of all domains was above 0.89, except the health domain, which shows high internal consistency. These results were consistent with the German, Korean, and Dutch validation studies (12–14).

According to our study, the construct validity of the

CPCHILD ranged between good and very good, except the health domain, which has 3 items. The health domain assesses the child’s health status and frequency of hospital admissions/visits, and these questions are not always the most important determinants of QoL for all children with CP.

For concurrent validity, domain scores and the total score of the CPCHILD were significantly different according to patients’ GMFCS levels. The CPCHILD was able to discriminate between the groups. The only exception for this was the health domain. This result is different from the original validation study (16), but similar to the German and Dutch validation studies (12, 14).

There are some limitations of this study. First, although the CHQ was designed for the evaluation of QoL of children with disabilities, it is not specific for children with CP. It can be inadequate for severely affected children with CP. In previous studies, families reported that some of the questions involved in CHQ PF-50 were not suitable for severely affected children with CP (25, 26).

Second, the CPCHILD was completed in accordance with the information received from the family. The educational and emotional status of parents may affect the results of the questionnaire. In our study, 50% of the caregivers had a low level of education (none, primary-secondary school). This might have an effect on the results of our study. As stated in the original study, it would be more effective if data from HRQoL evaluations were obtained directly from children instead of families. However, many

**Table 4. Concurrent validity of the scale by using GMFCS levels (ANOVA analysis)**

CPCHILD	GMFCS levels			p
	III (n=26) (Mean±SD)	IV (n=30) (Mean±SD)	V (n=26) (Mean±SD)	
Personal care & ADLs	45.7±22.1	33.5±18.05	28.07±20.0	<0.001 <sup>a</sup>
Positioning, transfer and mobility	78.40±25.71	58.71±32.56	41.62±22.70	<0.001 <sup>a</sup>
Communication and social interaction	63.81±31.03	59.24±30.98	32±18.05	<0.001 <sup>a</sup>
Comfort, emotions and behavior	37.48±22.78	33.98±24.09	28.87±23.27	<0.001 <sup>a</sup>
Health	92.22±27.90	88±05.28.76	42.77±31.71	0.11
Overall quality of life	60.66±15.29	60±16.97	43±20±13.75	<0.001 <sup>a</sup>
Total score	63.04±20.23	55.57±20.23	36.05±7.15	<0.001 <sup>a</sup>
Statistics of the total score	p1			
	p2			
	p3			

GMFCS: Gross Motor Function Classification System; CPCHILD: Caregiver Priorities and Child Health Index of Life with disabilities. <sup>a</sup>p<0.05; p1: Significant differences between levels III and IV. p2: Significant differences between levels IV and V. p3: Significant differences between levels III and V

of the children with severe CP have significant cognitive impairments, which makes this impossible. Nevertheless, for those children who are able, a child version of the CPCHILD will be useful and its validity should be assessed in further studies.

In children with non-walking and severely affected CP, children and caregiver needs can be significantly affected in many different ways. It also requires a versatile and multidisciplinary approach. For this reason, determination of the parameters affecting the QoL and problems experienced by severely affected children and caregivers are of great importance in determining rehabilitation goals. We aimed to study the validity and reliability of the Turkish version of the CPCHILD scale that we developed to close this gap in the literature. It is an important reference for future studies and rehabilitation program targets to be implemented. CPCHILD is able to help the effectiveness of rehabilitation programs and follow-up on the development of children, record changes in caregivers, observe how QoL is affected, and set new goals. In our country, there is a need to develop new scales that can assess HRQoL and the caregiving burden in children who are severely handicapped with chronic disabilities, and more work needs to be done to adapt the existing international scales to the Turkish language.

## Conclusion

The Turkish version of CPCHILD was found to be a reliable and valid questionnaire for the evaluation of HRQoL of children with moderate and severe CP. This study also showed that CPCHILD could be easily used both for research and clinical settings. There is a need for further studies on the development of new scales that can effectively assess caregiver burden for children who cannot walk and are severely affected, HRQoL, and/or the adaptation of scales developed for use in international studies to the Turkish language.

**Acknowledgements:** We thank all of the participants.

**Ethics Committee Approval:** All procedures performed 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. This study was approved by the Abant İzzet Baysal University Clinical Research Ethics Committee (2011/13).

**Informed Consent:** Written informed consent was obtained from the parents who participated in this study.

**Peer-review:** Externally peer-reviewed.

**Author Contributions:** Concept - T.T.Ş.; Design - T.T.Ş.; Supervision T.T.Ş., U.N.; Funding - T.T.Ş., E.T.Y., M.S.; Materials - E.T.Y., M.S.; Data Collection and/or Processing - E.T.Y., M.S.; Analysis and/or Interpretation - T.T.Ş.; Literature Review - T.T.Ş., E.T.Y., M.S.; Writing - T.T.Ş., B.A.; Critical Review - T.T.Ş., B.A., U.N.

**Conflict of Interest:** The authors have no conflicts of interest to declare.

**Financial Disclosure:** The authors declared that this study has received no financial support.

**Teşekkür:** Tüm katılımcılara teşekkür ederiz.

**Etik Komite Onayı:** Yapılan tüm işlemler Araştırma Komitesi'nin etik standartları, 1964 yılında yayınlanan Helsinki Bildirgesi ve sonraki eklerine uygun bir şekilde gerçekleştirilmiştir. Bu çalışma için etik kurul onayı Abant İzzet Baysal Üniversitesi Tıp Fakültesi Girişimsel Olmayan Klinik Araştırmalar Etik Kurulu'ndan alınmıştır (2011/13).

**Hasta Onamı:** Yazılı onam bu çalışmaya katılan annelerden alınmıştır.

**Hakem Değerlendirmesi:** Dış bağımsız.

**Yazar Katkıları:** Fikir - T.T.Ş.; Tasarım - T.T.Ş.; Denetleme - T.T.Ş., U.N.; Veri Toplanması ve/veya İşlemesi - E.T.Y., M.S., T.T.Ş.; Analiz ve/veya Yorum - T.T.Ş.; Literatür Taraması - T.T.Ş., E.T.Y., M.S.; Yazıyı Yazan - T.T.Ş., B.A.; Eleştirel İnceleme - T.T.Ş., B.A., U.N.

**Çıkar Çatışması:** Yazarlar çıkar çatışması bildirmemişlerdir. Bu makalenin içeriğinden ve yazılmasından tek başına yazarlar sorumludur.

**Mali Destek:** Bu araştırma kamu, ticari veya kar amacı gütmeyen sektörlerdeki finansman kuruluşlardan özel bir hibe almamıştır.

## References

1. Chen KL, Wang HY, Tseng MH, et al. The Cerebral Palsy Quality of Life for Children (CP QOL-Child): evidence of construct validity. *Res Dev Disabil* 2013; 34: 994–1000.
2. Rosenbaum P, Paneth N, Leviton A, et al. A report: The definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl* 2007; 109: 8–14.
3. Pellegrino LA, Ortolan EV, Magalhães CS, Viana AA, Narayanan UG. Brazilian Portuguese translation and cross-cultural adaptation of the “Caregiver Priorities and Child Health Index of Life with Disabilities” (CPCHILD) questionnaire. *BMC Pediatr* 2014; 14: 30.
4. Jaspers E, Verhaegen A, Geens F, Van Campenhout A, Desloovere K, Molenaers G. Lower limb functioning and its impact on quality of life in ambulatory children with

- cerebral palsy. *Eur J Paediatr Neurol* 2013; 17: 561–7.
5. The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization. *Soc Sci Med* 1995; 41: 1403–9.
  6. Chen KL, Tseng MH, Shieh JY, Lu L, Huang CY. Determinants of quality of life in children with cerebral palsy: a comprehensive biopsychosocial approach. *Res Dev Disabil* 2014; 35: 520–8.
  7. Narayanan UG, Fehlings D, Weir S, Knights S, Kiran S, Campbell K. Initial development and validation of the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD). *Dev Med Child Neurol* 2006; 48: 804–12.
  8. Viehweger E, Robitail S, Rohon MA, et al. Measuring quality of life in cerebral palsy children. *Ann Phys Rehabil Med* 2008; 51: 129–37.
  9. Landgraf JM, Maunsell E, Speechley KN, et al. Canadian-French, German and UK versions of the Child Health Questionnaire: methodology and preliminary item scaling results. *Qual Life Res* 1998; 7: 433–45.
  10. Feldman AB, Haley SM, Coryell J. Concurrent and construct validity of the Pediatric Evaluation of Disability Inventory. *Phys Ther* 1990; 70: 602–10.
  11. Ravens-Sieberer U, Gosch A, Rajmil L, et al. KIDSCREEN-52 quality-of-life measure for children and adolescents. *Expert Rev Pharmacoecon Outcomes Res* 2005; 5: 353–64.
  12. Jung NH, Brix O, Bernius P, et al. German translation of the caregiver priorities and child health index of life with disabilities questionnaire: test-retest reliability and correlation with gross motor function in children with cerebral palsy. *Neuropediatrics* 2014; 45: 289–93.
  13. Zalmstra TA, Elema A, Boonstra AM, et al. Validation of the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) in a sample of Dutch non-ambulatory children with cerebral palsy. *Disabil Rehabil* 2015; 37: 411–6.
  14. Sung KH, Kwon SS, Narayanan UG, et al. Transcultural adaptation and validation of the Korean version of Caregiver Priorities & Child Health Index of Life with Disabilities (CPCHILD). *Disabil Rehabil* 2015; 37: 620–4.
  15. Terwee CB, Bot SD, de Boer MR, et al. Quality criteria were proposed for measurement properties of health status questionnaires. *J Clin Epidemiol* 2007; 60: 34–42.
  16. Narayanan UG, Livingston MH, Weir S, Fehlings D. Further validation of the Caregiver Priorities and Child Health Index of Life with Disabilities: a disease-specific measure of health-related quality of life in children with severe cerebral palsy. *Dev Med Child Neurol* 2006; 48: 46–9.
  17. Palisano RJ, Cameron D, Rosenbaum PL, Walter SD, Russell D. Stability of the gross motor function classification system. *Dev Med Child Neurol* 2006; 48: 424–8.
  18. Rentz AM, Matza LS, Secnik K, Swensen A, Revicki DA. Psychometric validation of the child health questionnaire (CHQ) in a sample of children and adolescents with attention-deficit/hyperactivity disorder. *Qual Life Res* 2005; 14: 719–34.
  19. Ozdogan H, Ruperto N, Kasapçopur O, et al. The Turkish version of the Childhood Health Assessment Questionnaire (CHAQ) and the Child Health Questionnaire (CHQ). *Clin Exp Rheumatol* 2001; 19: S158–62.
  20. Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *J Clin Epidemiol* 1993; 46: 1417–32.
  21. Ruperto N, Ravelli A, Pistorio A, et al. Cross-cultural adaptation and psychometric evaluation of the Childhood Health Assessment Questionnaire (CHAQ) and the Child Health Questionnaire (CHQ) in 32 countries. Review of the general methodology. *Clin Exp Rheumatol* 2001; 19: S1–9.
  22. Landis JR, Koch GG. The measurement of observer agreement for categorical data. *Biometrics* 1977; 33: 159–74.
  23. Feise RJ, Michael Menke J. Functional rating index: a new valid and reliable instrument to measure the magnitude of clinical change in spinal conditions. *Spine (Phila Pa 1976)* 2001; 26: 78–86.
  24. Aslan E, Karaduman A, Yakut Y, Aras B, Simsek IE, Yagly N. The cultural adaptation, reliability and validity of neck disability index in patients with neck pain: a Turkish version study. *Spine (Phila Pa 1976)* 2008; 33: E362–5.
  25. Liptak GS, O'Donnell M, Conaway M, et al. Health status of children with moderate to severe cerebral palsy. *Dev Med Child Neurol* 2001; 43: 364–70.
  26. Wake M, Salmon L, Reddihough D. Health status of Australian children with mild to severe cerebral palsy: cross-sectional survey using the Child Health Questionnaire. *Dev Med Child Neurol* 2003; 45: 194–9.

## Apendix 1

## CPCHILD® Engellilik ile Yaşamda Bakıcı Öncelikleri & Çocuk Sağlığı Endeksi

### Yönergeler

1. Bu anket sizin sağlığınız, rahatınız ve iyilik haliniz ile ihtiyaçlarınızı karşılamamız hakkındadır.
2. Lütfen yönergeleri dikkatlice okuyunuz.
3. Lütfen tüm sorulara size en uygun olan rakamı daire içine alarak işaretleyiniz. Tüm yorum ve/veya eklemek istediklerinizi her sorunun altındaki boşluğa yazabilirsiniz.

### Örnek:

		YARDIM SEVİYESİ							
						T	O	M	B
						A	R	İ	A
						A	T	G	Ç
						M	A	Ö	I
						E	L	Z	M
						N	/	E	S
								T	I
								İ	L
								M	L
								E	L
									E
Aşağıdaki aktivitelerin her birini ne <b>sıklıkla</b> yaptığınızı düşünün.									
Bu aktiviteleri son 2 hafta içinde ne kadar <b>zorlukla</b> yaptığınızı değerlendirin, <b>ve</b> bu aktiviteleri yapmanıza yardımcı olması için ihtiyaç duyduğunuz <b>yardım düzeyini</b> seçin.									
Geçtiğimiz 2 hafta boyunca aşağıdakiler ne kadar zordu?	Mümkün değil (Neredeyse İmkansız)	Çok Zor	Biraz Zor	Çok Kolay	Hiç Problem Olmaksızın	0	1	2	3
1. Ayak giysisi/cihazları kullanımı? (çorap, ayakkabı, ortez, vb.)	0	1	2	3	4	5	6		

Yukarıdaki örnekte, ayak giysileri / cihazları kullanımı *çok kolay* olarak değerlendirilmiştir, ve ayak giysisi / cihazları kullanımı için *minimal / gözetimle* seviyede desteğe ihtiyacınız olduğu işaretlenmiştir.

4. Her kısmın sonunda, ankette rahatınız ve iyilik haliniz için önemli olduğuna inandığınız ve eksik gördüğünüz öğeleri ekleyebileceğiniz, bir boşluk bulunmaktadır.

Adınız: \_\_\_\_\_

Tarih: \_\_\_\_\_



## 1. KISIM: KİŞİSEL BAKIM / GÜNLÜK YAŞAM AKTİVİTELERİ

YARDIM SEVİYESİ

Aşağıdaki aktivitelerin her birini ne <b>sıklıkla</b> yaptığınızı düşünün. Bu aktiviteleri son 2 hafta içinde ne kadar <b>zorlukla</b> yaptığınızı değerlendirin ve bu aktiviteleri yapmanıza yardımcı olması için ihtiyaç duyduğunuz <b>yardım düzeyini</b> seçin.								T A M A M E N	O R T A	M İ N İ M A L E / T İ M L E	B A Ğ İ M S İ Z
<i>Mümkün değil</i> (Neredeyse İmkansız)		Çok Zor	Zor	Biraz Zor	Kolay	<i>Hiç</i> Çok Kolay Olmaksızın					
<b>1. Kendisi/başkası tarafından beslenme?</b> (en sık kullanılan yol ör. ağız <u>veya</u> tüple <u>veya</u> her ikisi)	0	1	2	3	4	5	6	0	1	2	3
<b>2. Ağız hijyenini koruma?</b> (ağız ve dişleri temiz tutma)	0	1	2	3	4	5	6	0	1	2	3
<b>3. Banyo yapma / yıkama?</b>	0	1	2	3	4	5	6	0	1	2	3
<b>4. Tuvalet kullanımı?</b> (mesane & barsak fonksiyonları, hijyen vb.)	0	1	2	3	4	5	6	0	1	2	3
<b>5. Bez/iç çamaşırını değiştirme?</b>	0	1	2	3	4	5	6	0	1	2	3
<b>6. Üstünü giyip/ çıkarma?</b> (gömlek, ceket, vb.)	0	1	2	3	4	5	6	0	1	2	3
<b>7. Altını giyip/çıkarma?</b> (pantolon, eşofman altı, vb.)	0	1	2	3	4	5	6	0	1	2	3
<b>8. Ayak giysisi/cihaz kullanımı?</b> (çorap, ayakkabı, ortez, vb.)	0	1	2	3	4	5	6	0	1	2	3
<b>9. Saç bakımı</b> (yıkama, kurutma, tarama/şekil verme, örme vb.)	0	1	2	3	4	5	6	0	1	2	3
<b>1A. Diğer kişisel bakım aktivitesi?</b> Belirtin: _____	0	1	2	3	4	5	6	0	1	2	3
<b>1B. Diğer kişisel bakım aktivitesi?</b> Belirtin: _____	0	1	2	3	4	5	6	0	1	2	3

## 2. KISIM: POZİSYONLAMA, TRANSFER & YER DEĞİŞTİRME

Aşağıdaki aktivitelerin her birini ne <b>sıklıkla</b> yaptığınızı düşünün. Bu aktiviteleri son 2 hafta içinde ne kadar <b>zorlukla</b> yaptığınızı değerlendirin, ve bu aktiviteleri yapmanıza yardımcı olması için ihtiyaç duyduğunuz <b>yardım düzeyini</b> seçin.								YARDIM DÜZEYİ				
Gectiğimiz 2 hafta boyunca, aşağıdakiler ne kadar zordu?	<i>Mümkün değil</i> (Neredeyse İmkansız)		<i>Çok Zor</i>	<i>Zor</i>	<i>Biraz Zor</i>	<i>Kolay</i>	<i>Çok Kolay</i>	<i>Hiç Problem Olmaksızın</i>	T A M A M E N	O R T A	M İ N İ M G Ö Z E T İ M L E	B A Ğ I M S I Z
10. Yatağa yatıp/kalkma?	0	1	2	3	4	5	6	0	1	2	3	
11. Tekerlekli/normal sandalyeye geçip/kalkma?	0	1	2	3	4	5	6	0	1	2	3	
12. Sandalyeye oturma?	0	1	2	3	4	5	6	0	1	2	3	
13. Egzersiz için ayakta durma?	0	1	2	3	4	5	6	0	1	2	3	
14. Ev içinde dolaşma? (mümkün olan her şekilde)	0	1	2	3	4	5	6	0	1	2	3	
15. Dış mekanda dolaşma? (mümkün olan her şekilde)	0	1	2	3	4	5	6	0	1	2	3	
16. Motorlu taşıtlara binip/inme? (araba, minibüs veya otobüs)	0	1	2	3	4	5	6	0	1	2	3	
17. Halka açık yerleri gezme? (park, tiyatro, dolaşma, vb.)	0	1	2	3	4	5	6	0	1	2	3	
2A. Diğer aktivite? Belirtin: _____	0	1	2	3	4	5	6	0	1	2	3	
2B. Diğer aktivite? Belirtin: _____	0	1	2	3	4	5	6	0	1	2	3	

## 3. KISIM: KONFOR &amp; DUYGULAR

							ŞİDDET			
	<i>Hergün</i>	<i>Çok Sık</i>	<i>Oldukça Sık</i>	<i>Birkaç Kez</i>	<i>Bir veya İki Kez</i>	<i>Hiçbir Zaman</i>	ŞİDDET Lİ	ORTA	HAFİF	HİÇ
<b>Geçtiğimiz 2 hafta boyunca, ne sıklıkla ağrı veya rahatsızlık hissi yaşadınız?</b>										
18. Kendiniz/başkası tarafından beslenirken?	0	1	2	3	4	5	0	1	2	3
19. Tuvalet kullanımı sırasında? (mesane & barsak fonksiyonları, hijyen, bezlenme, vb.)	0	1	2	3	4	5	0	1	2	3
20. Giyinip/soyunurken?	0	1	2	3	4	5	0	1	2	3
21. Yer veya pozisyon değiştirirken?	0	1	2	3	4	5	0	1	2	3
22. Otururken?	0	1	2	3	4	5	0	1	2	3
23. Yatakta uzanırken?	0	1	2	3	4	5	0	1	2	3
24. Uykunuzu bozan?	0	1	2	3	4	5	0	1	2	3
3A. Diğer aktivite sırasında? Belirtin: _____	0	1	2	3	4	5	0	1	2	3
3B. Diğer aktivite sırasında? Belirtin: _____	0	1	2	3	4	5	0	1	2	3
<b>Geçtiğimiz 2 hafta boyunca, ne sıklıkla böyle hissettiniz?</b>										
25. Tedirgin, hüzünlü, veya sinirli	0	1	2	3	4	5	0	1	2	3
26. Mutsuz veya üzgün	0	1	2	3	4	5	0	1	2	3

#### 4. KISIM: İLETİŞİM KURMA & SOSYAL ETKİLEŞİM

Aşağıdaki aktivitelerin her birini **ne sıklıkla** yaptığınızı düşünün.

Bu aktiviteleri son 2 hafta içinde ne kadar **zorlukla** yaptığınızı değerlendirin

<b>Gectiğimiz 2 hafta boyunca, ne bunlarda kadar zorluk yaşadınız?</b>	<i>Mümkün değil</i>						<i>Hiç</i>
	<i>(Neredeyse İmkansız)</i>	<i>Çok Zor</i>	<i>Zor</i>	<i>Biraz Zor</i>	<i>Kolay</i>	<i>Çok Kolay</i>	<i>Problem Olmaksızın</i>
<b>27. Ebeveninizi/bakıcınızı anlayabilme?</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>28. Ebeveyniniz/bakıcınız tarafından anlaşılabilme?</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>29. Sizi iyi tanımayan kişilerle iletişim kurarken?</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>30. Tek başınıza oynarken?</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>31. Diğerleri ile oynarken?</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>32. Okula/bakım merkezine giderken?</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>33. Hobi aktivitelerine (yüzme, aile ve arkadaşlar ile vakit geçirme, vb.) katılırken?</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>4A. Diğer sosyal aktivitelerde?</b> Belirtin: _____	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>4B. Diğer sosyal aktivitelerde?</b> Belirtin: _____	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>

### 5. KISIM: SAĞLIK

Son 2 hafta içinde	<i>En uygun seçeneği daire içine alınız.</i>					
<b>34. Kaç kere doktora veya hastaneye gitmek zorunda kaldınız?</b>	<i>7 günden fazla</i>	<i>7 günden az</i>	<i>3 veya daha fazla</i>	<i>İki kez</i>	<i>Bir kez</i>	<i>Hiç</i>
_____	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

Son 2 hafta içinde	<i>Çok Kötü</i>	<i>Kötü</i>	<i>Orta</i>	<i>İyi</i>	<i>Çok İyi</i>	<i>Mükemmel</i>
<b>35. Genel sağlığınızı nasıl değerlendirirsiniz?</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
_____						

**36. Son 2 hafta içinde aldığınız ilaçları listeleyiniz.**

**0. İlaç kullanmıyorum**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_
6. \_\_\_\_\_
7. \_\_\_\_\_
8. \_\_\_\_\_
9. \_\_\_\_\_

### 6. KISIM: GENEL YAŞAM KALİTENİZ

Son 2 hafta içinde	<i>Çok Kötü</i>	<i>Kötü</i>	<i>Orta</i>	<i>İyi</i>	<i>Çok İyi</i>	<i>Mükemmel</i>
<b>37. Genel yaşam kalitenizi nasıl değerlendirirsiniz?</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
_____						



### 7. KISIM: HER BİR ÖGENİN YAŞAM KALİTENİZDEKİ ÖNEMİ

Her bir ögenin yaşam kaliteniz için ne kadar önemli olduğu hakkındaki görüşleriniz nelerdir?	Çok					
	En az	Önemli	Biraz	Oldukça	Çok	En
	Önemli	Değil	Önemli	Önemli	Önemli	Önemli
1. Kendisi / başkası tarafından beslenme	0	1	2	3	4	5
2. Ağız hijyenini sağlama	0	1	2	3	4	5
3. Banyo yapma / yıkanma	0	1	2	3	4	5
4. Tuvalet kullanımı / hijyeni	0	1	2	3	4	5
5. Bez / iç çamaşırı değiştirme	0	1	2	3	4	5
6. Üstünü giyip / çıkarma	0	1	2	3	4	5
7. Altını giyip / çıkarma	0	1	2	3	4	5
8. Ayak giysilerini/cihazlarını giyme	0	1	2	3	4	5
9. Saç bakımı / tarama	0	1	2	3	4	5
10. Yatağa yatma / kalkma	0	1	2	3	4	5
11. Tekerlekli / normal sandalyeye geçme / kalkma	0	1	2	3	4	5
12. Tekerlekli /normal sandalyede oturma	0	1	2	3	4	5
13. Egzersiz için kalkma / yer değiştirme	0	1	2	3	4	5
14. İç mekanda dolaşma	0	1	2	3	4	5
15. Dış mekanda dolaşma	0	1	2	3	4	5
16. Motorlu taşıtlara binme / inme	0	1	2	3	4	5
17. Halka açık yerlere gitme	0	1	2	3	4	5
18. Beslenme sırasındaki konfor	0	1	2	3	4	5
19. Tuvalet kullanım sırasındaki konfor	0	1	2	3	4	5
20. Giyinip / soyunma sırasındaki konfor	0	1	2	3	4	5
21. Yer / pozisyon değiştirme sırasındaki konfor	0	1	2	3	4	5
22. Oturma sırasındaki konfor	0	1	2	3	4	5
23. Yatma sırasındaki konfor	0	1	2	3	4	5
24. Uyuma sırasındaki konfor	0	1	2	3	4	5
25. Duygusal durum veya davranışlar	0	1	2	3	4	5
26. Mutluluk	0	1	2	3	4	5
27. Bakıcımızı anlayabilme	0	1	2	3	4	5
28. Bakıcımız tarafından anlaşılabilme	0	1	2	3	4	5
29. Diğerleri ile iletişim kurabilme	0	1	2	3	4	5
30. Yalnız başına oynayabilme	0	1	2	3	4	5
31. Diğerleri ile oynayabilme	0	1	2	3	4	5
32. Okula / bakım merkezine gidebilme	0	1	2	3	4	5
33. Hobi ve yaratıcı aktivitelere katılabilme	0	1	2	3	4	5
34. Doktor randevularını ve hastanede kalış süresini azaltabilme	0	1	2	3	4	5
35. Genel sağlık	0	1	2	3	4	5
36. İlaç sayısını en aza indirebilme	0	1	2	3	4	5

<b>8. KISIM: HAKKINIZDAKİ BİLGİLER</b>
--

<b>1. Cinsiyetiniz:</b>	<input type="checkbox"/> Erkek <input type="checkbox"/> Kadın
<b>2. Doğum tarihiniz nedir?</b>	____ / ____ / ____ Gün    Ay    Yıl
<b>3. Şu ana kadar tamamladığınız en yüksek okul derecesi nedir? (sadece tek seçenek işaretleyiniz)</b>	Okul öncesi    ____ Anaokulu        ____ 1. Sınıf         ____ 2. Sınıf         ____ 3. Sınıf         ____ 4. Sınıf         ____ 5. Sınıf         ____ 6. Sınıf         ____ 7. Sınıf         ____ 8. Sınıf         ____ 9. Sınıf         ____ 10. Sınıf        ____ 11. Sınıf        ____ 12. Sınıf        ____ Okur-yazar     ____

**Sadece bu anketi tamamlamanız ne kadar sürdü?(birim zaman olarak): \_\_\_\_\_**

**KATILIMINIZ İÇİN TEŞEKKÜR EDERİZ!**