

## RESEARCH ARTICLE

# Caregiver burden in cerebral palsy: Validity and reliability of the Turkish version of caregiver difficulties scale

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## Abstract

**Background:** This study aims to translate the caregiver difficulties scale (CDS) into Turkish language and to reveal its reliability and validity in Turkish informal family caregivers of children with cerebral palsy (CP).

**Methods:** This study included 130 participants ( $39.9 \pm 7.8$  years; range 24–58 years; 106 females and 24 males). Demographic properties of participants, relationship with the care recipient, income, caregiving time, CP type and diseases of the child (e.g., epilepsy, hydrocephalus and congenital heart disease) and the caregiver were recorded. The CDS, caregiver well-being scale (CWBS), World Health Organization Quality of Life (WHOQOL-BREF) and Beck depression inventory (BDI) were used for data collection. The internal consistency of the CDS was assessed using the calculation of Cronbach's alpha coefficient. A test–retest interval of 2 weeks was used to assess the reliability. The intercorrelation of variables was evaluated using the Spearman correlation coefficient. The receiver operating characteristic (ROC) analysis was performed to find the predictive power of CDS scores for depression.

**Results:** A total of 130 family caregivers of children with CP completed the test/retest procedures. The Cronbach alpha coefficients were found as 0.878 for the test and 0.852 for the retest. Intraclass correlation coefficient (ICC) value was found between 0.83 and 0.90 for test–retest reliability of the CDS. In addition, the CDS showed a significantly strong correlation with CWBS-activities of living subscale and WHOQOL-BREF psychological, physical and environment domains, as well as a significantly moderate correlation with CWBS basic needs subscale, BDI and WHOQOL-BREF general health and social domains. CDS scores that are  $>46$  resulted in a sensitivity of 81.48% and a specificity of 73.79% for moderate–severe depression.

**Conclusion:** The Turkish version of the CDS is a valid and reliable measure for caregiver burden of family caregivers of children with CP.

## KEYWORDS

caregiver burden, cerebral palsy, reliability, validity

## 1 | INTRODUCTION

Informal caregivers are defined as family members, friends, neighbours and so forth who help someone with a chronic illness or disability that will create long-term care needs. Informal caregivers have no special training and are not paid (Guets et al., 2020). Caring for individuals with chronic diseases imposes a variety of responsibilities on caregivers (Putman & Ravin, 1994). Repeated hospital visits and prolonged hospitalization of children with chronic diseases can cause emotional, social and economic difficulties for the child and the caregiver (Dambi, Chivambo, et al., 2015a; Wicky et al., 2000). Studies found that the health and its related quality of life in informal caregivers are negatively affected (Dambi & Jelsma, 2014; Raina et al., 2005).

Cerebral palsy (CP) is a neurodevelopmental condition in the brain that affects muscle tone, balance and muscle control and causes limitations in participation (McInerney et al., 2017). CP is a clinical condition with a heterogeneous structure due to damage to the developing brain (Aisen et al., 2011). CP can be accompanied by spasticity, behavioural abnormalities and cognitive and speech disorders, as well as problems with nutrition and gastrointestinal functions (Aisen et al., 2011), which significantly limits daily activities. Therefore, children with CP need caregivers to a large extent in their daily life (Dambi, Chivambo, et al., 2015a).

Providing care to individuals with chronic diseases and meeting their needs places burden and various responsibilities on the caregivers (Chiou et al., 2009). Caregiver burden is defined as 'the burden or strain on a person who provides care to a disabled family member' (Oh & Lee, 2009). The age of the child, hospitalization frequency, dependence level, pain existence and care duration is associated with the high burden on the caregiver (de Moura et al., 2015; Javalkar et al., 2017). Difficulties in social relations, family and spouse relationship deterioration, limited freedom, interruption of sleep due to the needs of the child and economic strain are the most common problems seen in parents of children with CP (Davis et al., 2010). Functional disability further increases with the growth of the child, and as time progresses, the burden on the caregiver increases (Dambi, Chivambo, et al., 2015a; Pousada et al., 2013; Raina et al., 2004). Among the difficulties experienced by parents of children with CP are managing their children's daily living needs, such as self-care and mobility (Pashmdarfard et al., 2017). In addition, families have the responsibility of scheduling and coordinating the time of rehabilitation and medical check-ups (Palisano et al., 2010; Raina et al., 2005). These additional responsibilities were found to affect the physical and psychological health of parents of children with CP (Palisano et al., 2010).

Caregivers of disabled children have a big role with responsibilities, such as meeting their needs, making decisions on their behalf, accompanying them and being their defender, and these responsibilities are associated with the burden of care (Dambi et al., 2016). A negative impact on caregiver health due to this burden can lead to worse functional consequences in children with CP. Regularly evaluating the caregiver burden is important for children with disabilities to have good functional results (Dambi & Jelsma, 2014; Dambi, Jelsma, &

### Key messages

- Caregivers may fail to manage the effects of care on them, and their quality of life can be reduced.
- To improve the quality of life of caregivers of children with cerebral palsy, a tool may be useful to assess the caregiver's condition due to the burden of care.
- The Turkish version of the caregiver difficulties scale is valid and reliable for evaluating the burden among caregivers of children with cerebral palsy.

Mlambo, 2015b). A tool for caregivers of children with CP can be useful to identify appropriate support services for the caregiver and assess the caregiver's condition due to chronic burden (Wijesinghe et al., 2013). Based on our literature review, the caregiver difficulties scale (CDS) was identified as a useful screening scale that is easily filled up by CP caregivers in rehabilitation clinics that assess caregiver burden and include all its aspects (Wijesinghe et al., 2013). Caregiver burden is generally assessed with the Zarit Caregiver Burden (İnci & Erdem, 2008) scale and Bakas Caregiving Outcomes Scale in Turkey (Can, 2010). The Turkish validity and reliability of the Zarit Caregiver Burden scale were evaluated in caregivers of the elderly and the Bakas Caregiving Outcomes Scale in caregivers of patients with stroke, idiopathic Parkinson's disease, multiple sclerosis and spinal cord injury. CP is considered a prototype in paediatric disability (Aisen et al., 2011). A tool developed to assess the burden of caregivers of children with CP could also assess caregivers of children with other physical disabilities (Wijesinghe et al., 2013). Additionally, a self-administered questionnaire designed for the principal caregiver of the child with CP and specifically evaluating the care burden has not been determined in Turkey.

Therefore, this study aimed to translate the CDS into Turkish and evaluate the validity and reliability of the Turkish version of the CDS compared with the caregiver well-being scale (CWBS), World Health Organization Quality of Life Scale (WHOQOL-BREF) and Beck depression inventory (BDI) in family caregivers of children with CP.

## 2 | MATERIALS AND METHODS

### 2.1 | Study design

This research is a cross-sectional and methodological study that investigates the reliability and validity of the Turkish version of CDS.

### 2.2 | Setting and participants

Participants who applied to the inpatient rehabilitation clinic of a tertiary care hospital (Istanbul, Turkey) were included. Inclusion criteria were having a child who is 4–16 years old with CP, being the parents

of the client and being the person most concerned with the daily care of a child with CP. This study included 130 participants (39.9 ± 7.8 years; 106 females and 24 males) who met these inclusion criteria. Exclusion criteria were (Guets et al., 2020) pregnancy, (Putman & Ravin, 1994) cognitive impairment (at a level that prevents understanding and answering simple questionnaires), (Wicky et al., 2000) severe psychiatric illness, (Dambi, Chivambo, et al., 2015a) neurologic disorders, (Raina et al., 2005) providing additional care for another person with a disability, (Dambi & Jelsma, 2014) paid caregivers and (McInerney et al., 2017) could not speak, read and understand Turkish and nonnative Turkish speakers. Written and verbal information was given to all participants. Written consent was obtained from the participants. The study was approved by the University of Health Sciences Hamidiye scientific research ethics committee (Approval number: 20/477).

### 2.3 | Data collection

Demographic properties of participants, relationship with a client who is care recipient, caring time (year), income, CP type and main diseases of the child and the caregiver were recorded.

### 2.4 | Questionnaires

The CDS consists of 25 items, which were classified into 4 domains as concerns for the child (8 items), impact on self (7 items), caregiving support (5 items) and social and economic strain (5 items). Each item was scored on a 5-point (0–4) Likert scale indicating the frequency/extent of each caregiving experience as perceived by the caregivers. The final total score ranges from 0 to 100. A high score (for Sinhalese version of CDS is above 42) indicates a high caregiver burden (Wijesinghe et al., 2013; Wijesinghe et al., 2015).

The CWBS has been developed as a tool to evaluate the current status of caregivers in clinical care. The scale aims to measure the daily functional levels of caregivers, including basic needs and vital activities. Moreover, it can be used as a means of intervention for the caregiver to initiate emotional, physical or financial changes in his/her life with the burden of care. Three versions of the CWBS are available. Tebb developed CWBS (Tebb, 1995), Rubio et al. found that the two subscales for well-being were higher-ordered factors (Rubio et al., 1999) and Berg-Weger et al. revisited the scale (Berg-Weger et al., 2000). The original version includes 45 items that determine basic needs and life activities. The original form of the CWBS was utilized in this study. Greater scores indicate decreased depression levels and better well-being. The Turkish version of the CWBS has been determined to be reliable and valid (Berg-Weger et al., 2000; Demirtepe & Bozo, 2009).

BDI comprises 21 items that determine the risk of depression and measure the level of depressive symptoms and the change in severity. Each item is scored as 0–3, and the total score is expressed as their summation. The total ranges from 0 to 63. The patient is asked to

select one of four options in each category that is most suitable for him/her. The Turkish validity and reliability of the scale (Cronbach alpha coefficient  $r = .80$ ) were made by Hisli et al. (Hisli, 1989).

The WHOQOL-BREF is a health-related quality of life scale developed by the WHO. The validity and reliability of the Turkish Version of the WHOQOL-BREF were conducted by Eser et al. The scale has long (WHOQOL-100) and short (WHOQOL-27) forms. Subdimension scores are calculated from 4 to 20 since each subdimension expresses the quality of life in a certain field independently of each other. Quality of life increases with the scale score (Eser et al., 1999).

### 2.5 | Procedure

The CDS, CWBS, WHOQOL-BREF short form and BDI were completed by participants at the same time. All participants completed the CDS 2 weeks later for the second time.

### 2.6 | Translation and cross-cultural adaptation

Before starting the cross-cultural adaptation process, permission was obtained from the researcher who developed the CDS (Champa J. Wijesinghe, MD, Sri Lanka) via e-mail. The advice of Gjersing et al. (Gjersing et al., 2010) and IQOLA procedure (Aaronson et al., 1992) was used in this study. The Turkish translation of the original scale was done by independent two translators whose native language is Turkish. Another translator created the most appropriate translation form from the translations that are separately made. The common scale was translated back into English by two different translators. Then, with a team of linguists and professional translators, the formats that were translated into Turkish and translated back to English were examined. Interviews were conducted in all participants to ensure that all items were understandable. Then the final version was created and used to investigate the reliability and validity in caregivers of children with CP.

### 2.7 | Statistical analysis

Statistical analysis of the data was performed in International Business Machines Statistical Package for the Social Sciences Statics Version 24 (Corp, 2016). The consensus-based standards for the selection of health status measurement instruments guidelines were used as a guide in reporting the tool validation process (Mokkink et al., 2010). Test-retest consistency of CDS was evaluated by the Spearman rho correlation, and the test-retest difference was examined by the Wilcoxon signed-rank analysis. Sample size sufficiency for factor analysis was tested with the Kaiser–Meyer–Olkin (KMO) test, and the suitability of the data set for factor analysis was tested with the Barlett test; factor analysis was performed with Varimax rotation. The Cronbach alpha coefficient was used to evaluate the internal consistency between the items. Continuous data were not normally distributed (Kolmogorov–

Smirnov test,  $p < 0.05$ ); thus, the Mann-Whitney  $U$ -test was used to compare between two groups, and the Kruskal-Wallis  $H$  statistic (Mann-Whitney  $U$  with post hoc Bonferroni correction) was used to compare more than two groups. The relationship between the Turkish version of the CDS subdimension scores and other scale scores was evaluated using the Spearman correlation coefficient. ROC analysis was performed to find the predictive power of CDS scores for depression.  $P < 0.05$  was considered statistically significant.

### 3 | RESULTS

#### 3.1 | Characteristics of participants and comparison of other data

A total of 130 participants (106 females and 24 males) completed the study, which included the test-retest process. The age ranges from 24 to 58 years. Mothers of clients were providing more care (81.5%). Mean caring time was  $9.25 \pm 4.07$  years. The socio-economic status of the clients and the caregivers are presented in Table 1. The mean CDS score was  $47.38 \pm 13.54$  (6–78). The quality of life, BDI and CWBS scores are given in Table 2.

When the results of the test-retest correlation and Wilcoxon signed-rank analysis for answers on the CDS were examined, the calculated correlation coefficients for answers in the pretest and posttest range from 0.667 to 0.952, which were statistically significant ( $p < 0.05$ ). These results show that the scale questions were understandable to the participants involved in the research.

The CDS total and BDI scores of female participants were significantly higher than those of male participants, and the WHOQOL overall health and CWBS basic needs subdimensions scores of female participants were significantly lower than those of male participants ( $p < 0.05$ ). The CDS total and BDI scores of mothers were significantly higher than those of fathers ( $p < 0.05$ ). The WHOQOL overall health and CWBS basic needs subdimensions scores of mothers were significantly lower than those of fathers ( $p < 0.05$ ). The CDS total and BDI scores of those with low income were significantly higher than those with moderate income ( $p < 0.0167$ ).

The CDS total scores of participants providing care for '>10 years' were significantly higher than those providing care for '6–10 years' ( $p < 0.0167$ ). The WHOQOL social subdimension scores of those providing care for '>10 years' were significantly lower than those providing care for '6–10 years' ( $p < 0.0167$ ).

The CDS total scores of participants with 'minimal-mild depression (minimal depression score: 0–9 and mild depression score: 10–16)' were significantly lower than those with 'moderate-severe depression (moderate depression score: 17–19 and severe depression score: 30–63)' ( $p < 0.05$ ). The WHOQOL physical, social and environment and CWBS basic needs and life activities subdimension scores of participants with 'minimal-mild depression' were significantly higher than those with 'moderate-severe depression' ( $p < 0.05$ ).

The KMO and Bartlett's sphericity tests were applied to check the suitability of the sample size, and the result was found to be 0.77

**TABLE 1** The socio-economic status of the clients and the caregivers

	Number (n)	Percentage (%)
<b>Gender</b>		
Female/male	106/24	81.5/18.5
<b>Occupation</b>		
Housewife	85	65.4
Worker	26	20.0
Office worker	16	12.3
Artisan	3	2.3
<b>Education</b>		
Primary school	10	7.7
Secondary school	32	24.6
High school	69	53.1
University	19	14.6
<b>Marital status</b>		
Single/married	14/116	10.8/89.2
<b>Relationship with care recipient</b>		
Mother/father	106/24	81.5/18.5
<b>Income</b>		
Low	18	13.8
Moderate	106	81.5
High	6	4.6
<b>CP type</b>		
Hemiplegic	31	23.8
Diplegic	68	52.3
Quadriplegic	31	23.8
<b>Diseases of the child</b>		
Epilepsy	24	58.5
Asthma	4	9.8
Hydrocephalus	1	2.4
Scoliosis	6	14.6
Congenital heart disease	3	7.3
Down syndrome	3	7.3
<b>Diseases of the caregiver</b>		
Hypertension	16	50
Diabetes mellitus	12	37.5
Hypothyroidism	3	9.4
COPD	1	3.1

( $p < 0.001$ ). The statistical value of the sphericity test was 1555.27 ( $p = 0.00$ ,  $p < 0.05$ ).

#### 3.2 | Face validity

The final version of the questionnaire was presented to 25 participants by a face-to-face method for the questionnaire to be aimed at the target population. They were directed to read each item and evaluate

**TABLE 2** The mean scores of CDS, WHOQOL-BREF, Beck depression inventory and CWBS

Scale	Mean ± SD	Min-max
<b>CDS</b>	47.38 ± 13.54	6–78
<b>CWBS</b>		
Activities of living	76.28 ± 13.36	37–115
Basic needs	76.72 ± 12.48	43–107
<b>Beck depression inventory</b>	10.93 ± 7.34	0–34
<b>WHOQoL</b>		
General health	53.12 ± 21.18	0–100
Physical	44.28 ± 22.75	0–75
Psychological	33.62 ± 30.08	0–100
Social	49.12 ± 26.29	0–75
Environment	45.68 ± 17.76	0–75

Abbreviations: CDS, caregiver difficulties scale-Turkish; CWBS, caregiver well-being scale; SD, standard deviation; Min, minimum; Max, maximum; WHOQoL, World Health Organization Quality of Life.

the clear understanding of words, whether an extra explanation is necessary and ease of response (Anthoine et al., 2014).

### 3.3 | Internal consistency and test-retest reliability

Cronbach's alpha coefficient was used to measure the internal consistency of the CDS. The CDS was applied twice to all participants with an interval of 2 weeks since the clients were under our regular follow-up, and their parents were accessible. The intraclass correlation coefficient (ICC) was examined for test-retest reliability.

Answers to the CDS items revealed Cronbach alpha coefficients of 0.878 for the overall scale and between 0.886 and 0.881 for individual items in the first test and were 0.852 for the overall scale and between 0.840 and 0.868 for individual items in the retest. With these results, the scale was found to be highly reliable (0.00–0.4: not reliable; 0.40–0.60: low reliability; 0.60–0.80: quite reliable; and 0.80–1.00: highly reliable). According to the analysis of variance, scale items are additive ( $F = 42.715, p < 0.05$ ) (Table 3).

**TABLE 3** The internal consistency analysis

Item	Test		Retest	
	Item-total correlation	Cronbach's alpha	Item-total correlation	Cronbach's alpha
I1	0.458	0.874	0.430	0.846
I2	0.086	0.881	0.118	0.854
I3	0.426	0.875	0.363	0.848
I4	0.506	0.872	0.508	0.843
I5	0.547	0.871	0.552	0.841
I6	0.620	0.868	0.536	0.842
I7	0.432	0.875	0.443	0.845
I8	0.341	0.877	0.117	0.868
I9	0.577	0.870	0.600	0.841
I10	0.581	0.870	0.581	0.841
I11	0.412	0.875	0.482	0.844
I12	0.456	0.874	0.339	0.849
I13	0.634	0.869	0.639	0.840
I14	0.582	0.870	0.531	0.842
I15	0.558	0.871	0.624	0.841
I16	0.226	0.881	0.241	0.853
I17	0.370	0.876	0.346	0.849
I18	0.390	0.875	0.288	0.850
I19	0.339	0.876	0.240	0.851
I20	0.263	0.879	0.256	0.851
I21	0.594	0.870	0.488	0.844
I22	0.485	0.873	0.520	0.844
I23	0.315	0.877	0.276	0.851
I24	0.373	0.876	0.410	0.847
I25	0.451	0.874	0.430	0.846
		<b>0.878</b>		<b>0.852</b>

The reliability analysis revealed an ICC value between 0.83 and 0.90. Correlations were checked for the test–retest for each subscale. The test is concluded as reliable if the correlation is found positive and close to 1 (0.00–0.69 not reliable, 0.70–0.84 medium, 0.85–0.94 high and 0.95–1.00 excellent). In the present study, the correlation coefficients for all items were between 0.74 and 0.94 (Table 4).

### 3.4 | Construct validity

Construct validity was determined based on the relationship between CDS and CWBS, BDI, WHOQOL-BREF, age of the child, caregiver and caring time. It was assessed by Spearman's correlation coefficient.

For the construct validity, moderate to strong correlations were found between the CDS and other functional scales. A negative and significant correlation ( $p < 0.05$ ) was found between the CDS and CWBS and CDS and WHOQOL-BREF. Additionally, a positive correlation was detected between the BDI and CDS ( $p < 0.05$ ). No significant correlation was found between the CDS and the age of the child, caregiver and caring time. (Table 5).

### 3.5 | Sensitivity and specificity analysis

ROC curve analysis was conducted to establish the ability of the CDS scale to distinguish between symptoms of depression. The area under the curve (AUC) values that were calculated for the cut-off values of the CDS total scores in the diagnosis of moderate–severe depression were statistically significant ( $p < 0.05$ ). The CDS score of 46 or greater resulted in a sensitivity of 81.48 (95% confidence interval [CI]: 61.9–93.7) and a specificity of 73.79 (95% CI: 64.2–82.0).

## 4 | DISCUSSION

This study revealed the Turkish version of the CDS as internally consistent and highly reliable for test–retest.

Existing evidence suggests that caregiver burden is partially reduced when the needs and problems of the caregivers are frankly determined and the necessary precautions are taken (Acton & Kang, 2001). Caregiving has implications on the health of caregivers; thus, routine evaluation of caregiver burden is important (Dambi, Jelsma, & Mlambo, 2015b). Practical self-assessment questionnaires are needed to establish the requirement of further clinical evaluation

for the early identification of caregiver problems. The CDS can be considered an easy-to-apply and self-administered convenient tool for evaluating the different dimensions of caregiving burden in CP (Wijesinghe et al., 2013).

The Cronbach alpha coefficient of the original scale was reported as 0.911 based on the collected data during the scale development (Wijesinghe et al., 2013). A study by Farajzadeh et al. tested the Persian version of the CDS' (P-CDS) internal consistency and found the maximum Cronbach's alpha coefficient to be 0.887 (Farajzadeh et al., 2018). According to these findings, the Cronbach alpha coefficient for the whole scale was found to be 0.878 based on the answers given for the CDS questions. Cronbach's alpha coefficients of the CDS were found to be higher than the recommended value of 0.70 (highly reliable). Results could be compared with original validation findings, and Cronbach's alpha values were satisfactory and consistent with the original validation study.

Test–retest reliability measures the stability between administration of an assessment tool to the same groups twice at an appropriate time interval under the same conditions. Analysis of test–retest reliability in the original scale showed no significant difference between the CDS test and retest scores ( $t = 0.66$ ,  $P > 0.05$ ) (Wijesinghe

**TABLE 5** Construct validity of the CDS

	Spearman correlation coefficient	P value
Age of the caregiver	−0.106	0.229
Age of the child	0.002	0.979
Caring time	0.115	0.194
Family income	−0.284	0.001
<b>Caregiver well-being scale</b>		
Basic needs	−0.521	<0.0001
Activities of living	−0.609	<0.0001
Beck depression inventory	0.434	<0.0001
<b>WHOQoL scale</b>		
General health	−0.546	<0.0001
Physical	−0.608	<0.0001
Psychological	−0.831	<0.0001
Social	−0.516	<0.0001
Environment	−0.746	<0.0001

Abbreviations: CDS, caregiver difficulties scale-Turkish; CWBS, caregiver well-being scale; WHOQoL, World Health Organization Quality of Life.

Intraclass correlation <sup>b</sup>		95% confidence interval		F-test with true value 0			
		Lower bound	Upper bound	Value	df1	df2	Sig
Single measures	0.117 <sup>a</sup>	0.091	0.151	7.601	129	6321	.000
Average measures	0.868 <sup>c</sup>	0.834	0.899	7.601	129	6321	.000

<sup>a</sup>The estimator.

<sup>b</sup>Type C intraclass correlation coefficient.

<sup>c</sup>Interaction effect is absent.

**TABLE 4** Test–retest reliability (intraclass correlation coefficient)



et al., 2013). Farajzadeh et al. determined the P-CDS test–retest reliability to be acceptable (0.74–0.90), which indicates that the scale has reliable consistency (Farajzadeh et al., 2018). The test–retest reliability (ICC) of CDS-Turkish was found to be between 0.83 and 0.90. As obtained in the present study, the test is considered to be reliable if the correlation found is positive and close to 1.

Construct validity was evaluated by investigating the correlation between the CDS scores and BDI, CWBS, and WHOQOL-BREF scores. Farajzadeh et al. found a significant positive correlation between the P-CDS and BDI-II scores (Farajzadeh et al., 2018). In the present study, a positive correlation was found between the CDS-Turkish total and BDI scores ( $p < 0.05$ ). Similarly, Gugala et al. reported that the parents of children with CP had a high level of depression (Gugala et al., 2019). Scherer et al. reviewed 19 studies about parents of children with CP and showed that a positive correlation existed between parenting and depression symptoms in nearly all studies (Scherer et al., 2019). The caregivers of children with CP face challenges with psychologically negative effects that affect them as well as the children, and timely support can improve the health of caregivers. Meta-analysis of seven studies (662 participants) showed that interventions aimed at improving psychological well-being significantly improve parental well-being (Irwin et al., 2019).

A negative and statistically significant correlation was found between the CWBS and CDS scores ( $p < 0.05$ ). This result is consistent with the knowledge that taking care of a family member with chronic illness is a risk factor for some psychological problems (Gopalan & Brannon, 2006). As the caregiver burden increases, there may be a decrease in self-allotted time and leisure time, ability to perform household chores, adequate support and self-care, as shown by the assessment in the CWBS scale. Doctors caring for children with CP should be able to realize and evaluate problems, such as depression, caregiver health, social support and family functioning that may arise in caregiving family members. Self-assessment surveys are needed for the earlier detection of problems. Developing various intervention programmes is important for both caregiver and child health to identify areas where a person needs assistance to reduce care burden and subsequently help with these issues.

The original study revealed that the CDS and WHOQOL-BREF correlation analysis revealed a negative correlation between care burden and quality of life (Wijesinghe et al., 2013). Farajzadeh et al. found a negative correlation between the P-CDS and the quality of life that was evaluated by WHOQOL-BREF (Farajzadeh et al., 2018). Başaran et al. showed that caregivers of CP clients had lower quality of life in all domains of WHOQOL-BREF than controls (Basaran et al., 2013). Tseng et al. found significantly lower quality of life in all domains of the WHOQOL-BREF in caregivers of children with CP (excluding the environment domain) (Tseng et al., 2016). Similarly, in this study, a negative and statistically significant correlation was found between the WHOQOL-BREF and CDS-Turkish ( $p < 0.05$ ). Thus, identifying and evaluating interventions aimed at improving the well-being of caregivers is important as planning services for children with disabilities, as well as a greater need to improve the quality of life of caregiving family members.

Studies using the Sinhalese version of the CDS have shown that a high CDS score (over 42) predicts the psychological problems of the caregiver (Wijesinghe et al., 2013). Similarly, in this study, the AUC values were calculated for the cut-off values (CDS-Turkish score above 46) in the analysis applied to identify the ability of the CDS-Turkish to predict moderate–severe depression ( $p < 0.05$ ). Moreover, the CDS-Turkish will also be useful as a screening tool for identifying caregivers with problems, such as stress and depression.

The main limitation of the present study is the relatively small sample size since participants were only included from inpatient rehabilitation clinics. Further studies are needed with more caregivers of children with CP from other rehabilitation clinics to more accurately interpret the results.

In conclusion, implementing family-oriented interventions that are effective in reducing the burden of care is important, and therefore, practical self-assessment questionnaires are needed for clinical evaluation in family caregivers' rehabilitation clinics. With this purpose, we aimed to translate the CDS into Turkish. The findings of this study indicate that the CDS is valid and reliable for evaluating the burden among caregivers of children with CP.

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#### CONFLICT OF INTEREST

The authors report no conflicts of interest.

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#### AUTHOR CONTRIBUTIONS

Emel Atar: contributed to conception and design, contributed to analysis and interpretation, drafted manuscript, critically revised manuscript and gave final approval. Erdal Dilekçi: contributed to acquisition and analysis and gave final approval. Tuğba Özsoy Ünübol: contributed to analysis and interpretation and gave final approval. Nermin Gündüz: contributed to conception and gave final approval. Murat Atar: contributed to acquisition and analysis and gave final approval. Ayhan Aşkın: contributed to analysis and interpretation, critically revised manuscript and gave final approval.

#### ETHICS STATEMENT

The authors declared that the research was conducted according to the principles of the World Medical Association Declaration of Helsinki 'Ethical Principles for Medical Research Involving Human Subjects'. The study was approved by the Hamidiye Scientific Research Ethics Committee of University of Health Sciences with approval number: 20/477 (E-46418926-050.01.04--3070). Written informed consent was obtained from the patients who participated in this study.

## DATA AVAILABILITY STATEMENT

Datasets are available from the corresponding author at a reasonable request.

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## REFERENCES

- Aaronson, N. K., Acquadro, C., Alonso, J., Apolone, G., Bucquet, D., Bullinger, M., Bungay, K., Fukuhara, S., Gandek, B., Keller, S., Razavi, D., Sanson-Fisher, R., Sullivan, M., Wood-Dauphinee, S., Wagner, A., & Ware, J. E. Jr. (1992). International quality of life assessment (IQOLA) project. *Quality of Life Research*, 1(5), 349–351. <https://doi.org/10.1007/BF00434949>
- Acton, G. J., & Kang, J. (2001). Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis. *Research in Nursing & Health*, 24(5), 349–360. <https://doi.org/10.1002/nur.1036>
- Aisen, M. L., Kerkovich, D., Mast, J., Mulroy, S., Wren, T. A. L., Kay, R. M., & Rethlefsen, S. A. (2011). Cerebral palsy: Clinical care and neurological rehabilitation. *Lancet Neurology*, 10(9), 844–852. [https://doi.org/10.1016/S1474-4422\(11\)70176-4](https://doi.org/10.1016/S1474-4422(11)70176-4)
- Anthoine, E., Moret, L., Regnault, A., Sébille, V., & Hardouin, J. B. (2014). Sample size used to validate a scale: A review of publications on newly-developed patient reported outcomes measures. *Health and Quality of Life Outcomes*, 12, 176. <https://doi.org/10.1186/s12955-014-0176-2>
- Basaran, A., Karadavut, K. I., Uneri, S. O., Balbaloglu, O., & Atasoy, N. (2013). The effect of having a children with cerebral palsy on quality of life, burn-out, depression and anxiety scores: A comparative study. *European Journal of Physical and Rehabilitation Medicine*, 49(6), 815–822.
- Berg-Weger, M., Rubio, D. M., & Tebb, S. S. (2000). The caregiver well-being scale revisited. *Health & Social Work*, 25(4), 255–263. <https://doi.org/10.1093/hsw/25.4.255>
- Can, T. (2010). *Bakas Caregiving Outcomes Scale 'in (Bakas bakım verme etki ölçeği) Türkçe'ye uyarlanması, geçerlilik ve güvenilirliği*. Doktora Tezi, Pamukkale Üniversitesi Sağlık Bilimleri Enstitüsü, Denizli.
- Chiou, C. J., Chang, H. Y., Chen, I. P., & Wang, H. H. (2009). Social support and caregiving circumstances as predictors of caregiver burden in Taiwan. *Archives of Gerontology and Geriatrics*, 48(3), 419–424. <https://doi.org/10.1016/j.archger.2008.04.001>
- IBM Corp. (2016). *IBM SPSS Statistics for Windows, Version 24.0*. IBM Corp.
- Dambi, J., Chivambo, G., Chiwaridzo, M., & Matare, T. (2015a). Health-related quality of life of caregivers of children with cerebral palsy and minor health problems in Zimbabwe: A descriptive, comparative cross-sectional study. *International Journal of Scientific and Research Publications*, 5, 697–703.
- Dambi, J. M., & Jelsma, J. (2014). The impact of hospital-based and community based models of cerebral palsy rehabilitation: A quasi-experimental study. *BMC Pediatrics*, 14, 301. <https://doi.org/10.1186/s12887-014-0301-8>
- Dambi, J. M., Jelsma, J., & Mlambo, T. (2015b). Caring for a child with cerebral palsy: The experience of Zimbabwean mothers. *African Journal of Disability*, 4(1), 168. <https://doi.org/10.4102/ajod.v4i1.168>
- Dambi, J. M., Jelsma, J., Mlambo, T., Chiwaridzo, M., Dangarembizi-Munambah, N., & Corten, L. (2016). An evaluation of psychometric properties of caregiver burden outcome measures used in caregivers of children with cerebral palsy: A systematic review protocol. *Systematic Reviews*, 5, 42. <https://doi.org/10.1186/s13643-016-0219-3>
- Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., & Davern, M. (2010). The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. *Child: Care, Health and Development*, 36(1), 63–73. <https://doi.org/10.1111/j.1365-2214.2009.00989.x>
- de Moura, M. C., Wutzki, H. C., Voos, M. C., Resende, M. B. D., Reed, U. C., & Hasue, R. H. (2015). Is functional dependence of Duchenne muscular dystrophy patients determinant of the quality of life and burden of their caregivers? *Arquivos de Neuro-Psiquiatria*, 73(1), 52–57. <https://doi.org/10.1590/0004-282X20140194>
- Demirtepe, D., & Bozo, Ö. (2009). Caregiver well-being scale: A study of validity and reliability. *Turk Psychol*, 12, 38–40.
- Eser, E., Fidaner, H., Fidaner, C., Eser, S. Y., Elbi, H., & Göker, E. (1999). WHOQOL-100 ve WHOQOL-Bref'in Psikometrik Özellikleri. 3P (Psikiyatri Psikoloji Psikofarmakoloji). *Dergisi (Ek2)*, 7, 23–40.
- Farajzadeh, A., Amini, M., Maroufizadeh, S., & Wijesinghe, C. J. (2018). Caregiver difficulties scale (CDS): Translation and psychometric evaluation among iranian mothers of cerebral palsy children. *Occupational Therapy in Health Care*, 32(1), 28–43. <https://doi.org/10.1080/07380577.2017.1422607>
- Gjersing, L., Caplehorn, J. R., & Clausen, T. (2010). Cross-cultural adaptation of research instruments: Language, setting, time and statistical considerations. *BMC Medical Research Methodology*, 10, 13. <https://doi.org/10.1186/1471-2288-10-13>
- Gopalan, N., & Brannon, L. A. (2006). Increasing family members' appreciation of family caregiving stress. *The Journal of Psychology*, 140(2), 85–94. <https://doi.org/10.3200/JRPL.140.2.85-94>
- Guets, W., Al-Janabi, H., & Perrier, L. (2020). Cost-utility analyses of interventions for informal carers: A systematic and critical review. *Pharmacoeconomics*, 38(4), 341–356. <https://doi.org/10.1007/s40273-019-00874-6>
- Gugała, B., Penar-Zadarko, B., Pięciak-Kotlarz, D., Wardak, K., Lewicka-Chomont, A., Futyma-Ziaja, M., & Opara, J. (2019). Assessment of anxiety and depression in polish primary parental caregivers of children with cerebral palsy compared to a control group, as well as identification of selected predictors. *International Journal of Environmental Research and Public Health*, 16(21), 4173. <https://doi.org/10.3390/ijerph16214173>
- Hisli, N. (1989). Beck depresyon envanterinin üniversite öğrencileri için geçerliliği, güvenilirliği. *Psikoloji Dergisi*, 7, 3–13.
- İnci, F. H., & Erdem, M. (2008). Bakım verme yükü ölçeği' nin Türkçe'ye uyarlanması, geçerlilik ve güvenilirliği. *Atatürk Üniversitesi Hemşirelik Yüksekokulu Dergisi*, 11, 4.
- Irwin, L., Jesmont, C., & Basu, A. (2019). A systematic review and meta-analysis of the effectiveness of interventions to improve psychological wellbeing in the parents of children with cerebral palsy. *Research in Developmental Disabilities*, 95, 103511. <https://doi.org/10.1016/j.ridd.2019.103511>
- Javalkar, K., Rak, E., Phillips, A., Haberman, C., Ferris, M., & Van Tilburg, M. (2017). Predictors of caregiver burden among mothers of children with chronic conditions. *Children (Basel)*, 4(5), 39. <https://doi.org/10.3390/children4050039>
- McInerney, T. K., Adam, H. M., Campbell, D. E., DeWitt, T. G., Foy, J. M., & Kamat, D. M. (2017). *American Academy of Pediatrics Textbook of Pediatric Care* (2nd ed.). American Academy of Pediatrics. Chapter 226, Cerebral Palsy
- Mokkink, L. B., Terwee, C. B., Patrick, D. L., Alonso, J., Stratford, P. W., Knol, D. L., Bouter, L. M., & De Vet, H. C. W. (2010). The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: An international Delphi study. *Quality of Life Research*, 19(4), 539–549. <https://doi.org/10.1007/s11136-010-9606-8>
- Oh, H., & Lee, E. K. O. (2009). Caregiver burden and social support among mothers raising children with developmental disabilities in South Korea. *International Journal of Disability, Development and Education*, 56, 149–167. <https://doi.org/10.1080/10349120902868624>
- Palisano, R. J., Almars, N., Chiarello, L. A., Orlin, M. N., Bagley, A., & Maggs, J. (2010). Family needs of parents of children and youth with



- cerebral palsy. *Child: Care, Health and Development*, 36(1), 85–92. <https://doi.org/10.1111/j.1365-2214.2009.01030.x>
- Pashmdarfard, M., Amini, M., & Hassani, M. A. (2017). Participation of Iranian cerebral palsy children in life areas: A systematic review article. *Iranian Journal of Child Neurology*, 11(1), 1–12.
- Pousada, M., Guillamón, N., Hernández-Encuentra, E., Muñoz, E., Redolar, D., Boixadós, M., & Gómez-Zúñiga, B. (2013). Impact of caring for a child with cerebral palsy on the quality of life of parents: A systematic review of the literature. *Journal of Developmental and Physical Disabilities*, 25, 545–577. <https://doi.org/10.1007/s10882-013-9332-6>
- Putman, C. E., & Ravin, C. E. (Eds.) (1994). Textbook of diagnostic imaging. In *Chest Trauma* (2nd ed.) (pp. 591–599). WB Saunders Company.
- Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., Swinton, M., Zhu, B., & Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 115(6), e626–e636. <https://doi.org/10.1542/peds.2004-1689>
- Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., Russell, D., Swinton, M., King, S., Wong, M., Walter, S. D., & Wood, E. (2004). Caregiving process and caregiver burden: Conceptual models to guide research and practice. *BMC Pediatrics*, 4, 1. <https://doi.org/10.1186/1471-2431-4-1>
- Rubio, D. M., Berg-Weger, M., & Tebb, S. S. (1999). Assessing the validity and reliability of well-being and stress in family caregivers. *Social Work Research*, 23(1), 54–64. <https://doi.org/10.1093/swr/23.1.54>
- Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PLoS ONE*, 14(7), e0219888. <https://doi.org/10.1371/journal.pone.0219888>
- Tebb, S. (1995). An aid to empowerment: A caregiver well-being scale. *Health & Social Work*, 20(2), 87–92. <https://doi.org/10.1093/hsw/20.2.87>
- Tseng, M. H., Chen, K. L., Shieh, J. Y., Lu, L., Huang, C. Y., & Simeonsson, R. J. (2016). Child characteristics, caregiver characteristics, and environmental factors affecting the quality of life of caregivers of children with cerebral palsy. *Disability and Rehabilitation*, 38(24), 2374–2382. <https://doi.org/10.3109/09638288.2015.1129451>
- Wicky, S., Wintermark, M., Schnyder, P., Capasso, P., & Denys, A. (2000). Imaging of blunt chest trauma. *European Radiology*, 10(10), 1524–1538. <https://doi.org/10.1007/s003300000435>
- Wijesinghe, C. J., Cunningham, N., Fonseka, P., Hewage, C. G., & Østbye, T. (2015). Factors associated with caregiver burden among caregivers of children with cerebral palsy in Sri Lanka. *Asia-Pacific Journal of Public Health*, 27(1), 85–95. <https://doi.org/10.1177/1010539514548756>
- Wijesinghe, C. J., Fonseka, P., & Hewage, C. G. (2013). The development and validation of an instrument to assess caregiver burden in cerebral palsy: Caregiver difficulties scale. *The Ceylon Medical Journal*, 58(4), 162–167. <https://doi.org/10.4038/cmj.v58i4.5617>

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