



Turkish Version of Caregiver Difficulties Scale for the Children with Cerebral Palsy: A Study of Validity and Reliability

Hatice Adiguzel¹, Zekiye Ipek Katirci Kirmaci², Suat Erel³, Nevin Ergun³

¹Kahramanmaraş Sütçü İmam University, Faculty of Health Sciences, Department of Physiotherapy and Rehabilitation, Kahramanmaraş, Türkiye

²Gaziantep İslam, Science and Technology University, Faculty of Health Sciences, Department of Physiotherapy and Rehabilitation, Gaziantep, Türkiye

³Pamukkale University, School of Physical Therapy and Rehabilitation, Denizli, Türkiye

⁴SANKO University, Faculty of Health Sciences, Department of Physiotherapy and Rehabilitation, Gaziantep, Türkiye

Content of this journal is licensed under a Creative Commons Attribution-NonCommercial-NonDerivatives 4.0 International License.



Abstract

Aim: The purpose of this study is to evaluate the validity and reliability of the Turkish version of the Caregiver Difficulties Scale (CDS).

Material and Method: The CDS was translated into Turkish (TR-CDS) and 116 caregivers of children with Cerebral Palsy (CP) (mean age: 37.20±10.36 years) completed the TR-CDS. Impact on Family Scale (IPFAM), World Health Organization Quality of Life–Brief Form (WHOQOL-BREF), Fatigue Severity Scale (FSS), Nottingham Health Profile (NHP), Beck Depression Inventory-II (BDI-II), and subscales and total impact score of TR-CDS were used for the construct validity. The internal consistency was assessed using Cronbach's alpha, and the test-retest reliability was assessed using the Intraclass Correlation Coefficient (ICC).

Results: For construct validity, all subscales of TR-CDS showed negative correlation with the WHOQOL-BREF and showed positive correlation with the IPFAM, FSS, NHP, and BDI-II. ICC the results of test-retest reliability analysis were for TR-CDS (total)=0.879, impact on self (CDS-IS)=0.843, support for caregiving (CDS-SC)=0.759, social and economic difficulties (CDS-S&E)=0.827, and concern for the child (CDS-CC)=0.707. A value of 0.936 was found for internal consistency.

Conclusion: It was revealed that the TR-CDS was a valid and reliable tool for the caregivers of children with CP.

Keywords: Caregiver difficulties scale, cerebral palsy, caregivers, reliability, validity

INTRODUCTION

Cerebral Palsy (CP) is the most prevalent, non-progressive pediatric disease and a disturbance of movement, tone, and posture with a frequency of 2-3/1000 among live births (1). While motor dysfunctions differ in terms of clinical types, behavioral and sensory issues, speech impairments, and cognitive issues accompanies (1,2).

The family plays a central role in the lives of both the children and the team, contingent on the children's needs and dependency levels (1,3). The major goal of CP children's therapy is to help them become more adept at improving their adaptive abilities. Since the family plays a crucial role in ensuring that these children participate actively in life, family-centered approaches to CP rehabilitation are leading the field in this regard (4). Because of this, ensuring family engagement and identifying and addressing their needs and issues during interdisciplinary treatments is essential to the effectiveness of rehabilitation. Depending

on how inadequate their physical skills are, people with CP may require assistance with Activities of Daily Living (ADL) at different degrees (2). Widespread concern, money issues, time constraints, and limitations in social and cultural activities are all faced by caregivers of children with CP (2,5,6). While some families adjust to this circumstance quite well, others find it difficult to cope and make the necessary modifications. As a result, the caregivers' quality of life and life satisfaction decline, and their general wellbeing deteriorates. Therefore, assessing caregivers with physical, psychological, or social issues, as well as in terms of a lower quality of life for individuals with CP is crucial (4). Considering important caregivers, especially mothers, is one of the best ways to manage a children with CP and their handicap (6). These children live longer, and as a result, their families face more material, spiritual, physical, and social challenges. Eventually, family members eventually have behavioral and psychological difficulties. Due to the restricted availability of basic amenities and care services for the disabled, families in

CITATION

Adiguzel H, Katirci Kirmaci ZI, Erel S, Ergun N. Turkish Version of Caregiver Difficulties Scale for the Children with Cerebral Palsy: A Study of Validity and Reliability. *Med Records*. 2024;6(1):124-31. DOI:1037990/medr.1375252

Received: 15.10.2023 **Accepted:** 24.01.2024 **Published:** 30.01 2024

Corresponding Author: Hatice Adiguzel, Kahramanmaraş Sütçü İmam University, Faculty of Health Sciences, Department of Physiotherapy and Rehabilitation, Kahramanmaraş, Türkiye

E-mail: fzthati@gmail.com

developing nations are increasingly vulnerable to the detrimental effects of providing care (7).

The International Classification of Functioning, Disability and Health-Children and Youth (ICF-YH) acknowledges that the family's functioning is a fundamental environmental aspect that might impact the child's health and functionality (8). The ICF defines "participation" in life and highlights the importance of coping mechanisms for both adults and children who have incapacitating conditions (3). But caregivers are one of the most vulnerable groups in society which negatively affects caregivers and children with disabilities and makes it difficult to receive primary assistance and institutions in developing nations (9). As a result, family-centered and compassionate approaches to family members—particularly mothers—have a big influence on legislators, support organizations, campaigners, and others who support the rights of kids with disabilities. But, caregivers' accountability additionally plays a part in this role (9). In order to give caregivers access to chances and accurate support, it is required to measure the duties of care. This can only be done by employing questionnaires that assess a suitable caregiver's challenges in order to comprehend the family burden (9). It's very common practice to assess caregivers using questionnaires. The Caregiver Difficulties Scale (CDS) has gained prominence recently (10). It assesses all duties that are unique to caregivers of children with CP and covers them completely. Some of the scales like Zarit Caregiver Burden Scale (ZCBS) and Impact on Family Scale (IPFAM) can be used to evaluate the distress experienced by caregivers of children with CP (11,12). ZCBS scale was developed to assess the level of stress and impact of the disease in caregivers of elderly or dependent individuals. This scale was developed for relatives of Alzheimer's patients. The items of ZCBS generally address the social and emotional domains. The IPFAM was designed to measure the impact of pediatric chronic health conditions on family. Also it is longer than CDS, and scoring of the IPFAM is difficult. But CDS is a questionnaire designed to be completed by the principal caregiver of children with CP. Each subscale represents a major area of caregiver concerns and a high cumulative score obtained for a particular subscale is usually indicative of the area needing interventions. Sinhalese version of CDS showed that a high CDS score (above 42) is predictive of caregiver psychological problems. Therefore, CDS will also be useful as a potential screening tool for identification of caregivers who are at risk of psychological problems such as stress, depression and anxiety in Türkiye. This study aimed to develop the TR-CDS and to examine whether it is a valid and reliable tool for assessing the impact of having a child with CP.

MATERIAL AND METHOD

Study Design

This study is a methodological research.

Translation Procedures

The questionnaire was translated into Turkish and culturally adjusted as the first stage of the study. The validity and

reliability analysis was the second phase. The concepts of Beaton et al. and Guillemin et al. were applied during the cultural adaptation process (7,13). Two independent physical therapists (PT) who knew English and were native Turkish speakers translated the questionnaire into Turkish. Together, these two PTs with clinical backgrounds in working with caregivers of children with CP, developed the TR-CDS. Two native English speakers who were unaware of the first form of the questionnaire translated it back into English. In a follow-up discussion, two translators and two physiotherapists decided to employ the Turkish translation in the pilot program. To that end, 15 caregivers were invited to fill out the questionnaire and explain the challenges they encountered with each item. Consequently, the questionnaire's final form was made.

Individuals

The study included the caregivers of children with CP who were enrolled in outpatient rehabilitation centers and underwent physiotherapy and rehabilitation, were 1-18 ages and have any other neurological or systemic diseases. The caregivers of children with CP were between the ages of 17 and 65 (n=116). Caregivers who were on neuroleptic and antidepressant medication, could not speak Turkish, or were caregivers with a documented or treated mental illness who were judged unable to complete the questionnaire were excluded from the study. All of the comorbidities, parental risk factors (diabetes, blood pressure, heart disease, and smoking), surgeries, and applications of botulinum toxin (Btx) of CP children were noted, along with the demographic information of the caregivers and the children (Figure 1).

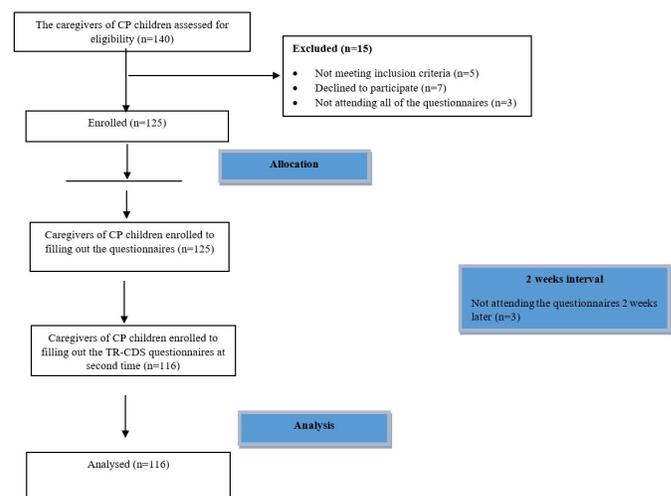


Figure 1. Flowchart of the study

Primary investigator administered the TR-CDS to caregivers of children with CP (10). The caregivers were also asked to fill in the World Health Organization Quality of Life-Brief Form (WHOQOL-BREF), Impact on Family Scale (IPFAM), Beck Depression Inventory-II (BDI-II), Nottingham Health Profile (NHP), and Fatigue Severity Scale (FSS) for the validity of TR-CDS (14-17). CDS's subscales consist of support for caregiving, impact on self, social and economic strain, and concerns for the

child. The CDS is similar to the IPFAM survey in terms of its subparameters. However, CDS is also predictive of caregiver psychological problems. In this respect, the BDI-II was used for the validity of the TR-CDS. NHP shows the quality of life in relation to their health, however the WHOQOL-BREF is as a valid and reliable alternative for the assessment of the quality of life people with long-term mental health conditions. Considering CDS questionnaire and subparameters, WHOQOL-BREF and NHP tests were used because they were thought to be related to the caregivers' quality of life. FSS was used because it shows caregivers' long-term effects on the disease in terms of fatigue levels which shows impact on self.

Two weeks later, the same caregivers were given the TR-CDS questionnaire once more for the reliability.

The caregivers were given all of the surveys to complete at the same time. All of the questionnaires took an average of forty-five minutes.

Prior to the data collection, every caregiver signed an informed consent form. The SANKO University Clinical Research Ethics Committee granted the study ethical permission (2019/01). The study registered with the clinical trial number of NCT04037137.

Measurements

Caregiver Difficulties Scale (CDS): One multifaceted instrument that can be utilized on its own is the CDS. It has 25 items (CDS-T). There are four subscales made out of the items: support for caregiving (CDS-SC) (5), impact on self (CDS-IS) (7), social and economic strain (CDS-S&E) (5), and concerns for the child (CDS-CC) (8). A total score between 0 and 100 is obtained by adding the scores of each item, which are rated on a 5-point scale (0–4) that represents the frequency and intensity of each caring encounter as reported by the caregivers. A high score indicates that the caregiver was over burden (10).

Impact on Family Scale (IPFAM): The impact of the burden on caregivers was measured using the Turkish version of the IPFAM. The 33-item IPFAM inventory takes ten to fifteen minutes to finish. A score of 4 (strongly agree) to 1 (strongly disagree) is assigned to each item. Six items assess the impact of the impaired child on siblings, while 27 items gauge the overall effect on the family. The IPFAM subscales include financial support (IPFAM-FS), coping (IPFAM-C), disruption of social relationships (IPFAM-SR), and overall impact (IPFAM-TI). Low impact is indicated by low scores (11). The validity and reliability (ICC=0.95) of this questionnaire are shown in the Turkish version (11).

Nottingham Health Profile (NHP): NHP evaluated the caregivers' quality of life in relation to their health. The NHP is a subjective measure of health that assesses suffering in the following subgroups: social isolation (5), mobility (8), pain (8), emotional reactions (9), sleep (5), and energy (3). Every subgroup has a score ranging from 0 to 100. NHP's validity and reliability (ICC=0.87) are demonstrated in the Turkish version (18,19).

Fatigue Severity Scale (FSS): Nine items make up the FSS. The individuals was asked to indicate how much they agreed with each statement by selecting between 1 and 7. One score denotes a strong disagreement, while seven denotes a strong agreement. Severe weariness is often indicated by a score of 4 or higher. Nine is the lowest score while 63 is the best. A high score denotes a high level of weariness severity. Armutlu et al. carried out the validity and reliability assessment of the scale in Türkiye. Test-retest reliability exists for patients with multiple sclerosis (ICC=0.81), fibromyalgia (ICC: 0.94) and the scale's internal consistency was determined to be good (16,20).

Beck Depression Inventory-II (BDI-II): The Turkish version of the BDI- II was used. A general depressive state's associated behavior and emotions are measured with the 21-item Beck Depression Inventory (BDI) (ICC=0.90) (21).

World Health Organization Quality of Life-Brief Form (WHOQOL-BREF): Both the short version of WHOQOL-BREF and the long version of WHOQOL were employed; the WHOQOL-BREF is particularly helpful for clinical and service evaluations. Quality of life is defined by the World Health Organization (WHO) as "individuals' perceptions of their positions in life in the context of the culture and value systems in which they live and regarding their goals, expectations, standards, and concerns." This definition forms the basis of this measurement. The WHOQOLBREF is a legitimate and trustworthy substitute for the evaluation of individuals with chronic mental illnesses. It comprises a total of 26 questions with four categories: psychological, physical, social interactions, and environment. It is rated from 1 to 5 on a Likert-type scale, where higher numbers denote a higher quality of life. Every sub-parameter has a score between 0 and 100, where 100 represents the highest quality of life and 0 the lowest. Internal consistency, reliability, and construct validity (ICC=0.34) of the Turkish version of the measure are all rather good (22).

Statistical analysis

Statistical analyses were conducted using the IBM SPSS 24 package application (SPSS Inc., Chicago, IL, USA). When post-hoc power analysis was carried out, the link between CDS and IPFAM, one of the study's data, indicated that the study's power was 0.99 (G*Power 3.1, Düsseldorf, Germany). The correlation between the TR-CDS and NHP, FSS, IPFAM, BDI-II, and WHOQOL-BREF was used to assess the construct validity. Correlation coefficient values fall between -1.0 to 1.0. A computed value that is more than 1.0 or less than -1.0 indicates that the correlation measurement had an error. The total negative correlation is indicated by a correlation of -1.0, and whereas the perfect positive correlation is shown by a correlation of 1.0. Test-retest reliability and internal consistency were used to assess the reliability of the questionnaire. The Cronbach α value was used to assess internal consistency, and the intraclass correlation coefficient (ICC) and comparison of measurement scores at various times were used to assess test-retest reliability. An ICC score of less than

0.5 indicates poor reliability, a value between 0.5 and 0.75 indicates moderate reliability, a value between 0.75 and 0.9 indicates high dependability, and a value greater than 0.90 indicates outstanding reliability. For all statistical studies, the p value was evaluated at the 0.05 significance level. Based on the knowledge that the sample size should be at least 5-10 times of the number of surveys' items in validity and reliability studies, it was aimed to reach a sample size of 125 caregivers for the current study (23,24). But some of the caregivers didn't attend the questionnaires 2 weeks later. So the test-retest part of the study completed with the 116 caregivers of children with CP.

RESULTS

In this study, caregivers (n=116) were 94 (81%) female and 22 (19%) male, with a mean age of 37.20±10.36 years. The children were 59 (50.9%) female and 57 (49.1%) male, with a mean age of 7.10±5.08 years. Table 1 shows the sociodemographic information for each caregivers (Table 1).

Table 1. Sociodemographic information of the individuals in the study

| Variables | | (n=116) X±SD (Min-max) | |
|-------------------------------------|---------------|---------------------------|-----------|
| Age (year) | Parents | 37.20±10.36 (17-65) | |
| | Children | 7.10±5.08 (1-18) | |
| Weight (kg) | Parents | 72.60±18.10 (4-113) | |
| | Children | 31.77±22.26 (6-82) | |
| Height (cm) | Parents | 159.98±24.41 (165-185) | |
| | Children | 118.68±34.63 (130-175) | |
| Caregiver n (%) | Mother | 90 (77.6%) | |
| | Father | 18 (15.5) | |
| | Others | 8 (6.9) | |
| Caregivers' working status | Yes | 36 (68.96) | |
| | No | 80 (31.03) | |
| Sex | Male n (%) | 22 (19) | |
| | Female n (%) | Parents | 94 (81) |
| | | Children | 57 (49.1) |
| | Female n (%) | 59 (50.9) | |
| Education level of caregivers n (%) | Primary | 52 (44.8) | |
| | Secondary | 27 (23.3%) | |
| | High | 21 (18.1) | |
| | University | 16 (13.8) | |
| Type of CP | Hemiparetic | 34 (29.31%) | |
| | Diparetic | 37 (31.89%) | |
| | Quadriparetic | 25 (21.55%) | |
| | Dyskinetic | 17 (14.65%) | |
| | Mixt | 3 (2.58%) | |

n: number, %: percent, X: mean, SD: standard deviation, min: minimum, max: maximum, CP: cerebral palsy, kg: kilograms, cm: centimeters

Table 2 shows the mean of the sub-parameters for all tests as well as the mean of the test-retest of the TR-CDS sub-parameters (Table 2).

Table 2. Averages of TR-CDS parameters, IPFAM, NHP, WHOQOL-BREF (SR), and BDI-II test scores

| | Number of Items | Test X±SD (min-max) | Retest X±SD (min-max) |
|------------------|-----------------|---------------------------|--------------------------|
| CDS (CC) | 8 | 18.06±7.64 (2-30) | 17.79±9.85 (2-79) |
| CDS (IS) | 7 | 12.12±6.66 (0-27) | 11.44±6.85 (0-26) |
| CDS (SC) | 5 | 8.51±4.5 (0-20) | 8.06±4.72 (0-20) |
| CDS (S&E) | 5 | 8.49±4.19 (0-19) | 8.35±4.54 (0-19) |
| CDS (T) | 25 | 47.19±17.53 (3-83) | 45.66±19.65 (3-129) |
| | | Test X±SD (min-max) | |
| IPFAM (FS) | | 8.12±2.61 (3-12) | |
| IPFAM (GI) | | 25.5 5±6.52 (7-47) | |
| IPFAM (SR) | | 22.49±6.61 (9-42) | |
| IPFAM (C) | | 7.54±5.60 (3-61) | |
| IPFAM (TI) | | 48.25±12.55 (20-87) | |
| NHP (P) | | 30.44±32 (0-100) | |
| NHP (ER) | | 28.64±29.46 (0-100) | |
| NHP (S) | | 25.58±32.29 (0-100) | |
| NHP (SI) | | 20.96 ±29.22 (0-100) | |
| NHP (PA) | | 21.67±23.46 (0-88.46) | |
| NHP (E) | | 43.39±37.84 (0-100) | |
| NHP (T) | | 169.23±135 (0-510.59) | |
| FSS | | 4.15±2.39 (0-21) | |
| WHOQOL-BREF (GH) | | 50.29±21.63 (0-100) | |
| WHOQOL-BREF (PH) | | 61.54±20.85 (0-100) | |
| WHOQOL-BREF (PS) | | 61.24±18.09 (0-100) | |
| WHOQOL-BREF (SR) | | 56.64±25.74 (0-100) | |
| WHOQOL-BREF (E) | | 56.60±15.58 (9.37-106.25) | |
| BDI-II | | 15.07±10.79 (0-47) | |

CDS (CC): Caregiver Difficulties Scale (CDS)-concerns for the child, CDS (IS): CDS-Impact on self, CDS (SC): CDS-Support for caregiving, CDS (S&E): CDS-Social&Economic strain, CDS (T): CDS total, IPFAM (FS): IPFAM financial support, IPFAM (GI): IPFAM general impact, IPFAM (SR): IPFAM disorders of social relationship, IPFAM (C): IPFAM coping, IPFAM (TI): IPFAM total impact, NHP (P): Nottingham Health Profile (NHP)-pain, NHP (ER): NHP-emotional reactions, NHP (S): NHP-sleep, NHP (SI): NHP-social isolation, NHP (PA): NHP-physical activity, NHP (E): NHP-Energy, NHP (T): NHP-total, FSS: Fatigue Severity Scale, WHOQOL-BREF (GH): World Health Organization Quality of Life-Brief Form general health, WHOQOL-BREF (PH): Physical health, WHOQOL-BREF (PS): Psychological score, WHOQOL-BREF (SR): Social relationships, WHOQOL-BREF (E): Environment, BDI-II: Beck Depression Inventory- II

Strong construct validity was proven by the TR-CDS scale, as shown by the significant correlations with NHP, FSS, IPFAM, WHOQOL-BREF, and BDI-II as well as between total score (TR-CDS -T) and its subscales. There were no significant correlations found between the total score of TR-CDS and any of its subscales and IPFAM (C) (Table 3). TR-CDS (T) and IPFAM (TI) showed a moderately strong positive correlation ($r=0.454$, $p=0.000$); TR-CDS (IS) and BDI-II showed a moderately significant positive correlation ($r=0.555$, $p=0.000$); CDS (S&E) and IPFAM (FS) and IPFAM (SR) showed a moderately strong positive correlation ($r=0.534$, $p=0.000$); and NHP (SI) showed a significant

and good correlation ($r=0.308$, $p=0.001$). TR-CDS (T) and TR-CDS (IS) showed a moderate, significant, negative correlation ($r=-0.390$, $p=0.001$), as did WHOQOL-BREF (GH) ($r=-0.467$, $p=0.000$). And moderate strong positive correlation ($r=0.481$, $p=0.000$) was found between NHP (ER) and TR-CDS (T). Also moderate strong positive correlation ($r=0.483$, $p=0.000$) between TR-CDS (IS) and NHP (ER).

Strong moderate correlation was found between TR-CDS (T) and NHP (T) ($r=0.588$, $p=0.000$) (Table 3).

Cronbach's alpha for the TR-CDS total impact score was determined to be 0,936 (Table 4). The good test-retest reliability for the CDS subscales (ICC=0.707-0.879) were shown in Table 4.

Table 3. Spearman Correlation Coefficients Between TR-CDS and IPFAM, NHP, FSS, WHOQOL-BREF, BDI-II in caregivers of children with CP (n=116)

| | CDS (CC) | CDS (IS) | CDS (SC) | CDS (S&E) | CDS (T) |
|------------------|----------------------|----------------------|----------------------|----------------------|----------------------|
| | p (r) |
| IPFAM (FS) | $p<0.001^*$ (0.433) | $p<0.001^*$ (0.391) | 0.058 (0.177) | $p<0.001^*$ (0.534) | $p<0.001^*$ (0.511) |
| IPFAM (GI) | $p<0.001^*$ (0.325) | $p<0.001^*$ (0.382) | 0.041* (0.190) | $p<0.001^*$ (0.496) | $p<0.001^*$ (0.454) |
| IPFAM (SR) | $p<0.001^*$ (0.426) | $p<0.001^*$ (0.452) | 0.125 (0.143) | $p<0.001^*$ (0.550) | $p<0.001^*$ (0.526) |
| IPFAM (C) | 0.721 (0.034) | 0.970 (-0.004) | 0.5 (-0.063) | 0.608 (0.048) | 0.928 (0.009) |
| IPFAM (TI) | $p<0.001^*$ (0.337) | $p<0.001^*$ (0.399) | 0.158 (0.132) | $p<0.001^*$ (0.507) | $p<0.001^*$ (0.454) |
| NHP (P) | $p<0.001^*$ (0.320) | $p<0.001^*$ (0.457) | 0.006* (0.255) | $p<0.001^*$ (0.396) | $p<0.001^*$ (0.474) |
| NHP (ER) | 0.001* (0.313) | $p<0.001^*$ (0.483) | 0.011* (0.235) | $p<0.001^*$ (0.422) | $p<0.001^*$ (0.481) |
| NHP (S) | $p<0.001^*$ (0.378) | $p<0.001^*$ (0.438) | 0.3 (0.097) | $p<0.001^*$ (0.448) | $p<0.001^*$ (0.463) |
| NHP (SI) | 0.124 (0.144) | 0.001* (0.308) | $p<0.001^*$ (0.371) | 0.001* (0.292) | $p<0.001^*$ (0.345) |
| NHP (PA) | 0.019* (0.217) | 0.001* (0.311) | 0.110 (0.149) | 0.001* (0.306) | $p<0.001^*$ (0.325) |
| NHP (E) | $p<0.001^*$ (0.325) | $p<0.001^*$ (0.446) | 0.013* (0.230) | $p<0.001^*$ (0.404) | $p<0.001^*$ (0.467) |
| NHP (T) | $p<0.001^*$ (0.394) | $p<0.001^*$ (0.556) | 0.001* (0.308) | $p<0.001^*$ (0.526) | $p<0.001^*$ (0.588) |
| FSS | 0.005* (0.262) | 0.001* (0.293) | 0.347 (0.088) | 0.079 (0.164) | 0.002* (0.287) |
| WHOQOL-BREF (GH) | $p<0.001^*$ (-0.325) | $p<0.001^*$ (-0.390) | 0.001* (-0.300) | $p<0.001^*$ (-0.423) | $p<0.001^*$ (-0.467) |
| WHOQOL-BREF (PH) | 0.010* (-0.240) | $p<0.001^*$ (-0.326) | 0.481* (-0.066) | 0.019* (-0.218) | 0.001* (-0.297) |
| WHOQOL-BREF (PS) | 0.020* (0.216) | $p<0.001^*$ (-0.450) | 0.004* (-0.268) | 0.007* (-0.250) | $p<0.001^*$ (-0.393) |
| WHOQOL-BREF (SR) | 0.036* (-0.196) | 0.001* (-0.238) | $p<0.001^*$ (-0.382) | $p<0.001^*$ (-0.354) | $p<0.001^*$ (-0.358) |
| WHOQOL-BREF (E) | $p<0.001^*$ (-0.349) | $p<0.001^*$ (-0.349) | $p<0.001^*$ (-0.411) | $p<0.001^*$ (-0.410) | $p<0.001^*$ (-0.488) |
| BDI-II | $p<0.001^*$ (0.356) | $p<0.001^*$ (0.555) | $p<0.001^*$ (0.322) | $p<0.001^*$ (0.447) | $p<0.001^*$ (0.554) |

Pearson correlation, * $p<0,05$, r: correlation coefficient, CDS (CC): Caregiver Difficulties Scale (CDS)-concerns for the child, CDS (IS): CDS-Impact on self, CDS (SC): CDS-Support for caregiving, CDS (S&E): CDS-Social&Economic strain, CDS (T): CDS total, IPFAM (F): IPFAM financial support, IPFAM (GI): IPFAM general impact, IPFAM (SR): IPFAM disorders of social relationship, IPFAM (C): IPFAM coping, IPFAM (TI): IPFAM total impact, NHP (P): Nottingham Health Profile (NHP)-pain, NHP (ER): NHP-emotional reactions, NHP (S): NHP-sleep, NHP (SI): NHP-social isolation, NHP (PA): NHP-physical activity, NHP (E): NHP-Energy, NHP (T): NHP-total, FSS: Fatigue Severity Scale, WHOQOL-BREF (GH): World Health Organization Quality of Life–Brief Form general health, WHOQOL-BREF (PH): Physical health, WHOQOL-BREF (PS): Psychological score, WHOQOL-BREF (SR): Social relationships, WHOQOL-BREF (E): Environment, BDI-II: Beck Depression Inventory-II

Table 4. Internal consistency and test-retest reliability results of the TR-CDS

| n=116 | 2 assessments on 2 sessions with 15day interval | Caregivers | | | |
|-------------------------|---|-----------------|------------------|-------|-------------|
| | | Number of Items | Cronbach's Alpha | ICC* | 95% CI |
| Test-Retest Reliability | CDS1-2 (CC) | 8 | 0.828 | 0.707 | 0.603-0.787 |
| | CDS1-2 (IS) | 7 | 0.915 | 0.843 | 0.781-0.889 |
| | CDS1-2 (SC) | 5 | 0.863 | 0.759 | 0.670-0.827 |
| | CDS 1-2 (S&E) | 5 | 0.905 | 0.827 | 0.759-0.877 |
| | CDS 1-2 (T) | 25 | 0.936 | 0.879 | 0.830-0.915 |

*Two-way mixed-effect model on average measures with absolute agreement definition. CI: confidence interval, ICC: intra-class correlation coefficient, CDS1 (CC): first assessment of caregiver difficulties scale (CDS)-concerns for the child, CDS2 (CC): second assessment of the CDS-concerns for the child, CDS1 (IS): first assessment of the CDS-Impact on self, CDS2 (IS): second assessment of the CDS- Impact on self, CDS1 (SC): first assessment of the CDS-Support for caregiving, CDS2 (SC): second assessment of the CDS-Support for caregiving, CDS1 (S&E): first assessment of the CDS-Social&economic strain, CDS2 (S&E): second assessment of the CDS-Social&economic strain, CDS1 (T): first assessment of the CDS total, CDS2 (T): second assessment of the CDS total

DISCUSSION

The CDS, which assesses the challenges faced by caregivers of children with CP, was translated into Turkish in the current study, and the TR-CDS was also found to be valid and reliable in the Turkish population. Additionally, this study demonstrated the consistency and potential for measuring similar properties among all TR-CDS subscales.

Despite the fact that a lot of researches has been investigated the social, emotional, and financial implications of caring for children with CP, it was found that the majority of caregiver burden questionnaires were English. This is why the current study aimed to have the TR-CDS questionnaire first. This questionnaire was used in this study without any modifications, and it was determined that the Turkish population could easily interpret the questionnaire. Furthermore, TR-CDS is considered to be a useful screening tool for identifying caregivers who might be at risk for psychological problems such as stress, anxiety, and depression.

Establishing the validity of the Turkish version of the scale, which assesses the burden of caring for children with CP, was another important goal of the current study. Based on previous studies, factors such as a family's financial situation, educational level, the number of family members, age of the child, and the amount of time that caregivers spend with their children, raise stress levels, and increases the caregivers' burden (5,8,25). No relationship was found between the age of the children and any of the sub-parameters, specifically financial support in the current study. Nonetheless, the current study examined how the disease affected caregivers using five subscales. The construct validity of the TR-CDS was also established by using the correlation of the IPFAM total score. We can therefore state that IPFAM has good validity, with the exception of coping and total effect. The relationship found between the overall score of IPFAM and the total effect score of TR-CDS indicates that having a children with CP can serve as a good predictor of the caregiver's burden. It has also been demonstrated that when using comparable screening scales, the impact of children with CP on their caregivers can lead to parallel findings in terms of caregiver burden. The highest relationships between the IPFAM and TR-CDS subscales were seen in the IPFAM social relations, financial support, and IPFAM total effect, and TR-CDS total effect, and TR-CDS social or economic challenges. These results demonstrated the need for further in-depth research on the family's employment situation, level of financial assistance, and interpersonal relationships. There was no correlation between the TR-CDS subscales and IPFAM coping score. We think that the absence of questions about coping in the TR-CDS led to this result. CDS scale consists of the 4 subscales called concerns for the child, impact on self, Support for caregiving, social & economic strain. This result shows where CDS and IPFAM differ from each other. The IPFAM survey examines the family's ability to cope with the

problems, as well as the family's impact on the child's illness. Farajzadeh et al stated that all subscales of the CDS were positively correlated with the caregiver burden scale (CBS), BDI-II and FSS and negatively correlated with the WHOQOL-BREF similar to our study (9).

The strong correlations seen between the NHP total score, the TR-CDS subscales, and the overall score point to a detrimental effect on caregivers' health condition as caregiver burden rises. Analogous research has demonstrated a decline in health-related quality of life with an increase in caregiver burden (26).

The need for psychosocial support platforms to be developed in order to evaluate these people's depression levels is indicated by the strong correlations found between the BDI-II and the individual effect score and overall score of the TR-CDS subscales. These findings were discovered to be consistent with findings from other research investigations in the literature (27-29).

Compared to healthy groups, having a dependent kid and playing the role of caregiver to children with CP puts mothers and children under stress and increases the likelihood that depression may develop. The WHOQOL-BREF and TR-CDS domains displayed moderate, strong, and negative correlation, in line with previous research. It was discovered that these outcomes agreed with both the initial research of Carona et al. It was found to be similar to the results with this study. Carone et al. showed that quality of life was impacted by the stress of giving care in both direct and indirect ways. Caregivers experience a profound decline in their psychological and physical well-being and quality of life as the demands and challenges of providing care grow, leaving them feeling hopeless. Our findings support those of previous research, which found a connection between quality of life and caregiver burden of care (9,28,30,31). This demonstrated how caregivers' quality of life declined as their workload rose. With the exception of the psychological parameter, a negative connection was found between the overall scores for the WHOQOL-BREF domains and TR-CDS subscales. This finding demonstrated that psychological warfare and survival skills developed along with the child's caregivers' worry levels.

Cronbach's alpha values were found to be consistent and equivalent to the internal consistency values of the other versions of the CDS in terms of reliability results of the TR-CDS study (9,10). Cronbach α value for the total scale of TR-CDS was 0.911 similar to our study (0.936) (10). Cronbach α of 0.68-0.84 in all subscales indicated satisfactory internal consistency within each subscale (10). But our results in the current study had higher internal consistency levels within each subscale (0.828-0.915). Farajzadeh et al. was found the Cronbach α values of TR-CDS between 0.743-0.887 in total score and subscales (9). These results was similar to our study. It shows a quite satisfactory that these internal consistency results are higher for each subscale and total score of the

TR-CDS.

Test-retest reliability measures the questionnaire's stability over time by administering the same TR-CDS to the same subjects twice. Two-week interval was used in this research. Similar studies have noted that test-retest reliability measurements were obtained using parent interviews over a two-week interval (5,8,9,25). Test-retest reliability was assessed twice using the Intraclass Correlation Coefficient (ICC). Our study's results demonstrated excellent test-retest reliability, matching that of the CDS versions from Iran (9). ICC values was 0.743–0.848 in the Iranian version which is similar to our study (ICC=0.707-0.879). The results related to the reliability of this study were consistent with the results of the Iranian version of this scale.

For a global understanding of the measuring properties of these questions, it is imperative that the questionnaires be translated and validated into multiple languages. These investigations make it possible to safely administer the same questionnaires in cross-cultural comparison studies and in various cultural contexts (32-35). According to us, the TR-CDS can be used to evaluate the advantages and disadvantages of social services that help families transition to community life and support their children's rehabilitation process by measuring the stress experienced by caregivers of children with CP.

We think that this useful and simple-to-use questionnaire is crucial for assessing the burden that caregivers bear in relation to the anxiety of their children, their own effects, the care they receive, and social and economic challenges. It also helps to pinpoint the areas that require additional support for families.

A constraint of our research was that it was limited to four distinct Turkish cities that housed rehabilitation clinics. In this regard, it is thought that assessing the caregiver burden in cities with varying socio-cultural levels will more accurately represent Türkiye. Other cities and caregivers from different socioeconomic backgrounds could be included to help determine the caregiver burden profile and establish social support programs in Türkiye. Even though the caregivers in the rehabilitation center in this study were selected at random and satisfied the minimal requirements outlined by Fidell and Tabachnick (36), it is advised that more extensive sampling studies be carried out nationwide. Our study was further limited by the small number of fathers who provided primary care.

CONCLUSION

The present study's findings demonstrated the validity and reliability of the TR-CDS as a tool for assessing the difficulties that families and caregivers of children with CP bear. Test-retest scores, validity assessments, and total-sub-questionnaire correlations all demonstrate the usefulness of the TR-CDS as a family effect measurement instrument.

As the first study on the burden of care among Turkish

caregivers of children with CP, the current study revealed the TR-CDS scale's "good-excellent" psychometric qualities. TR-CDS can be used as a particular assessment instrument to evaluate the burden before planning some treatments to identify the requirements of caregivers of children with CP in Turkey and to minimize the caregivers burden. But further study is needed to determine the scale's applicability to other groups. Finding the responsibilities and challenges brought on by their size and care is one method to help these people live better lives. To calculate the care burden, a method that measures the dimensions of the weight of obligation is needed. Because of this, it can be a helpful tool in identifying caregiver issues due to its excellent psychometric qualities when combined with the TR-CDS 4 subscale.

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

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

Ethical approval: *The SANKO University Clinical Research Ethics Committee granted the study ethical permission (2019/01). The study registered with the clinical trial number of NCT04037137.*

REFERENCES

1. Ones K, Yilmaz E, Cetinkaya B, Caglar N. Assessment of the quality of life of mothers of children with cerebral palsy (primary caregivers). *Neurorehabil Neural Repair.* 2005;19:232-7.
2. Park, E-Y, Nam SJ. Time burden of caring and depression among parents of individuals with cerebral palsy. *Disabil Rehabil.* 2019;41:1508-13.
3. Vogts N, Mackey AH, Ameratunga S, Stott NS. Parent-perceived barriers to participation in children and adolescents with cerebral palsy. *J Paediatr Child Health.* 2010;46:680-5.
4. Basaran A, Karadavut KI, Uneri S, et al. The effect of having a children with cerebral palsy on quality of life, burn-out, depression and anxiety scores: a comparative study. *Eur J Phys Rehabil Med.* 2013;49:815-22.
5. Schaible B, Colquitt G, Caciula MC, et al. Comparing impact on the family and insurance coverage in children with cerebral palsy and children with another special healthcare need. *Child Care Health Dev.* 2018;44:370-7.
6. Tuna H, Unalan H, Tuna F, Kokino S. Quality of life of primary caregivers of children with cerebral palsy: a controlled study with Short Form-36 questionnaire. *Dev Med Child Neurol.* 2004;46:647-8.
7. Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine.* 2000;25:3186-91.
8. Majnemer A, Shevell M, Law M, et al. Indicators of distress in families of children with cerebral palsy. *Disabil Rehabil.* 2012;34:1202-7.
9. Farajzadeh A, Amini M, Maroufizadeh S, Wijesinghe CJ. Caregiver difficulties scale (CDS): translation and psychometric evaluation among iranian mothers of cerebral palsy children. *Occup Ther Health Care.* 2018;32:28-43.

10. Wijesinghe C, Fonseka P, Hewage C. The development and validation of an instrument to assess caregiver burden in cerebral palsy: caregiver difficulties scale. *Ceylon Med J*. 2013;58:162-7.
11. Bek N, Simsek IE, Erel S, et al. Turkish version of impact on family scale: a study of reliability and validity. *Health Qual Life Outcomes*. 2009;7:4.
12. Seng BK, Luo N, Ng WY, et al. Validity and reliability of the zarit burden interview in assessing caregiving burden. *Ann Acad Med Singap*. 2010;39:758-63.
13. 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.
14. Akvardar Y, Akdede BB, Özerdem A, et al. Assessment of quality of life with the WHOQOL-BREF in a group of Turkish psychiatric patients compared with diabetic and healthy subjects. *Psychiatry Clin Neurosci*. 2006;60:693-9.
15. Alonso J, Anto JM, Moreno C. Spanish version of the Nottingham Health Profile: translation and preliminary validity. *Am J Public Health*. 1990;80:704-8.
16. Armutlu K, Korkmaz NC, Keser I, et al. The validity and reliability of the Fatigue Severity Scale in Turkish multiple sclerosis patients. *Int J Rehabil Res*. 2007;30:81-5.
17. Storch EA, Roberti JW, Roth DA. Factor structure, concurrent validity, and internal consistency of the beck depression inventory—second edition in a sample of college students. *Depress Anxiety*. 2004;9:187-9.
18. Yildiz N, Topuz O, Gungen GO, et al. Health-related quality of life (Nottingham Health Profile) in knee osteoarthritis: correlation with clinical variables and self-reported disability. *Rheumatol Int*. 2010;30:1595-600.
19. Kucukdeveci AA, McKenna SP, Kutlay S, et al. The development and psychometric assessment of the Turkish version of the nottingham health profile. *Int J Rehabilitation Res*. 2000;23:31-8.
20. Gencay-Can A, Can SS. Validation of the Turkish version of the fatigue severity scale in patients with fibromyalgia. *Rheumatol Int*. 2012;32:27-31.
21. Uslu RI, Kapci EG, Oncu B, et al. Psychometric properties and cut-off scores of the Beck Depression Inventory-II in Turkish adolescents. *J Clin Psychol Med Settings*. 2008;15:225-33.
22. Eser E, Fidaner H, Fidaner C, et al. Psychometric properties of the WHOQOL-100 and WHOQOL-BREF. *J Psychiatry Psychol Psychopharmacol*. 1999;7:23-40.
23. Buyukozturk S. Factor analysis: basic concepts and using to development scale. *Kuram Ve Uygulamada Eğitim Yönetimi*. 2002;32:470-83.
24. Mishel MH. Methodological Studies: Instrument Development. In: Brink PJ, Wood MJ, eds, *Advanced design in nursing research*, 2nd edition, New Delhi: SAGE Publications, 1998;235-86.
25. Wijesinghe CJ, Cunningham N, Fonseka P, et al. Factors associated with caregiver burden among caregivers of children with cerebral palsy in Sri Lanka. *Asia Pac J Public Health*. 2015;27:85-95.
26. Simsek IE, Simsek TT, Erel S, Atasavun Uysal S. Factors affecting health related quality of life and depression levels of mothers in families having children with chronic disabilities. *HK J Paediatr (New Series)*. 2020;25:71-8.
27. Garip Y, Ozel S, Tuncer OB, et al. Fatigue in the mothers of children with cerebral palsy. *Disabil Rehabil*. 2017;39:757-62.
28. Khanna AK, Prabhakaran A, Patel P, et al. Social, psychological and financial burden on caregivers of children with chronic illness: a cross-sectional study. *Indian J Pediatr*. 2015;82:1006-11.
29. Pinquart M, Sorensen S. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. *J Gerontol B Psychol Sci Soc Sci*. 2003;58:112-28.
30. Carona C, Silva N, Crespo C, Canavarró MC. Caregiving burden and parent-child quality of life outcomes in neurodevelopmental conditions: the mediating role of behavioral disengagement. *J Clin Psychol Med Settings*. 2014;21:320-8.
31. Dambi JM, Jelsma J, Mlambo T, et al. An evaluation of psychometric properties of caregiver burden outcome measures used in caregivers of children with cerebral palsy: a systematic review protocol. *Syst Rev*. 2016;5:42.
32. Angold A, Costello EJ. The child and adolescent psychiatric assessment (CAPA). *J Am Acad Child Adolesc Psychiatry*. 2000;39:39-48.
33. Aybay C, Erkin G, Elhan AH, et al. ADL assessment of nondisabled Turkish children with the WeeFIM instrument. *Am J Phys Med Rehabil*. 2007;86:176-82.
34. Ruperto N, Ravelli A, Pistorio A, et al. Paediatric Rheumatology International Trials Organisation. 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.
35. Schmidt S, Bullinger M. Current issues in cross-cultural quality of life instrument development. *Arch Phys Med Rehabil*. 2003;84:S29-34.
36. Tabachnick BG, Fidell LS, Ullman JB. *Using multivariate statistics (Vol. 5)*: Pearson Boston, MA. 2007.