

## Research Article

# Translation, adaptation, and validation of caregiver difficulties scale in Urdu

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## ABSTRACT

**Background:** Even though there are extensive, studies carried out to assess the caregiver burden among caregivers of Cerebral Palsy children through different scales. Caregiver Difficulties scale (CDS) is designed for the specific population of CP's Caregivers. So, this scale is translated in Urdu to use on the parents of CP children in Pakistan.

**Objective:** To translate, adapt and validate the Caregiver Difficulties Scale into Urdu.

**Method:** There Descriptive Study was conducted on n=40 caregivers of Cerebral Palsy children. Males & Females (Specifically fathers & mothers) age ranged 30 to 60 from Rehabilitation Institute took part in the study. Caregiver difficulties scale (CDS) was used along with a demographic Performa for data collection.

**Results:** The caregiver difficulties scale is a reliable measure to assess the caregiver burden among caregivers of CP Children (Cronbach  $\alpha=0.91$ ). The correlation value ranges from  $r=0.88^{**}$  (Urdu to Urdu) to  $r=0.83^{**}$  (English to English) which shows that Urdu version have conceptual equivalence and cross language validity.

**Conclusion:** The translation and adaptation of the Caregiver Difficulties Scale (CDS) in Urdu is reliable and valid for assessment of caregiver giver difficulties in caregivers of cerebral palsy children

**Keywords:** cerebral palsy; caregivers; care giver burden.

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## History

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## INTRODUCTION

Translation and adaptation into native language is a process to make any scale easier and easily comprehensible. The rudimentary function of translating a scale is to communicate proper meaning of sentences linguistically, semantically and pragmatically. This multifaceted method is always completed in a professional way to make it simpler, easy to understand and comprehensible. Its basis goal is to make the translation more readable and easier to understandable [1].

From all neurodevelopmental disabilities Cerebral palsy (CP) is as lifelong childhood disability. The associated features are neurological issues, muscular spasticity, limb's flaccidity, cognitive dysfunction, speech problems, chewing & feeding difficulties, behavioural issues and gastrointestinal dysfunctions [2]. Number of cases of cerebral palsy (CP) were rising abruptly in Pakistan and its prevalence was twice then other diseases. 4 children out of 1,000 are suffered from CP as compared to a global average of 2 to 3 children per 1,000 (Published in The Express Tribune, 2020). CP children are extremely reliant on their caregivers (especially family) due to lifelong disability related issues. Upbringing & taking care of CP's are difficult, stressful and challenging responsibility for caregivers. Parents of CP's are under higher burden than parents of healthy children [3].

A caregiver is someone closely belongs to the child with Cerebral Palsy (CP), must be properly trained to take care of the biological, physical, and psychological needs of the child. Caregiver look after the child in activities of daily living such as giving them proper meal, medication, cleanliness, physical exercises & speech therapy, special education play, and leisure activities with the child [4]. Caregivers not only manage the children's activities of daily living, but also must pay attention to CP's altering health conditions, which are associated with modifications in the caregivers' life and negatively affect their mental wellbeing [5]. Due to multiple disability relates concerns and prolonged disability, children with CP become entirely dependent on their caregivers.

The caregiving burden in parents is mostly not addressed. Caregivers were also suffering from many psychological issues & social restrictions, i.e, the caregivers are stigmatized and feel socially isolated, and develop conflicts with family. Besides, all other mental health issues they also experience physical stress including disturbed sleep, bodily pain & aches, and blood pressure related medical issues. So, the ignored and neglected part in rehabilitation of disease is caregiving burden that must be understood clearly [6]. Caregivers aid a disabled person in those activities of daily living which a CP

child cannot be performed independently. This is the major cause of caregiver burden. Caregiver's attitudes towards disabilities have a great influence on their difficulties. If person providing care perceive it negatively, they can experience more psychological problems. Most of the caregivers of Cerebral palsy and children with other disability may need psychological support, assistance, and attention to manage caregivers' burden [7,17]. Research suggest that caregivers of CP children are more likely to experience emotional stress, mental despair, financial constraints and interpersonal difficulties [8]. Previous research on caregivers of CP also reported that high level of caregiver burden is mostly negatively effects the mental wellbeing, physical health, family functioning and social life that may leads to low quality of child's care and unfulfilled child's need [9]. Different studies already conducted in different countries including Sri Lanka, Iran and Turkish population to assess the validity and reliability of caregiver difficulties scale which reported that it is a reliable and valid measure to assess the caregiver burden. It is self-administered scale with multiple dimensions [10-12].

The main purpose of the current study was to translate, adapt and validate the Caregiver difficulties scale in Urdu to assess the caregiver burden. It was also aimed to measure the psychometric properties of the Urdu translated scale and administered on parents of children with cerebral palsy (CP) in Pakistan.

## METHODOLOGY

The caregivers of Cerebral Palsy children were included in study. The Board of Advanced study and Research (BASR) approved the research (IIUI/BASR-16-2021). The study was carried out in Psychology department NIRM (F No: NIRM/1-12-2022), Islamabad Pakistan. After taking permission and consent from the original author of Caregiver Difficulties Scale (CDS), translation of the CDS into Urdu language was started. Translation was carried out in four steps as First step was forward Translation 2nd was Committee Approach 3rd step was Back translation and forth and last was Committee Approach again.

*Phase I* The method to translate a scale can be possible only by involving a group of capable professionals who were skilled in languages [13]. Five professionals who were competent in languages (English & Urdu) were involved for the translation. Basic rationale of the research was briefed to the experts. Five professionals were selected from International Islamic University. Experts were briefed to focus on conceptual translation and not just merely words translation to use both brief and comprehensible language. To evaluate the forward (Urdu) translations Committee approach was adapted. A committee of five

members was constituted (n=5) to select the best translation of each item. All the members 3 clinical psychologists and 2 academicians in field of psychology did a careful review of all items in accordance with the original context. After extensive review of all items, no item was removed from scale based on content imbalance or cultural irrelevance. Backward translation of the scale was completed comprehensively. The scale which was finalized after committee approach was then shared with English Experts who were bilingual (n=5). All were MS in English and were not involved earlier in translation process. They were inquired to translate the scale in English. After receiving the backward translations, the linguistic and theoretical equivalence between actual scale and backward translated versions of the scales comprehensively evaluate by the previous committee. The Same committee who went through the forward translation procedure engaged again for this purpose. They found the equivalence between backward translated version and original scale. All the translated items conveyed the similar meaning to original items the committee concluded.

*Phase II (Cross language Validation)* Follow-up of translation language validation for the scale was done on sample of n=40 care givers of cerebral palsy children. The sample was divided into two groups. Group 1 was assessed on original English version and

group 2 was assessed on Urdu version. The scale was administered again bit differently to the same participants after 1 week. At that time each group was further divided into groups 1a (n=10) and 1b (n=10). In a same way Group 2 was divided into 2a (n=10) 2b (n=10).

Actual English version scale was given to group 1a and 2a while Urdu version scale was given to group 1b and 2b. Then Pearson's correlation was checked between two groups. For cross validation correlation was done between English and Urdu based Caregiver Difficulties Scale. To determine the psychometric properties of the translated version was applied on n=80 to check the internal consistency of the scale. Data was plotted on SPSS-21. By using SPSS reliability of the translated versions were determined.

## RESULTS

The result showed that there is correlation between both versions of Caregiver Difficulties Scale is significant ( $p < 0.01$ ). The correlation value ranges from 0.88\*\* (Urdu to Urdu) to 0.83\*\* (English to English). This reveals that scores on Urdu and English have significant positive correlation in both the groups. It indicates that original English and translated Urdu version of the Caregiver Difficulties Scale has significant high conceptual equivalence and cross language validity. (Table 1)

**Table 1: Cross language validation and test-retest reliability of Caregiver Difficulties scale (N=40)**

Groups	N	1 <sup>st</sup> Administration	2 <sup>nd</sup> Administration	r
I	10	English	English	0.83***
II	10	English	Urdu	0.83***
III	10	Urdu	Urdu	0.88***
IV	10	English	Urdu	0.84***

Level of significance:  $p < 0.01$ \*\*\*

The Alpha coefficient of the translated version of the Caregiver Difficulties Scale indicates that the

translated scale has acceptable range of skewness, kurtosis, and reliability. (Table 2)

**Table 2: Alpha coefficient of the translated version of the Caregiver Difficulties Scale (CDS) (N=80)**

Scale	k	M(SD)	$\alpha$	Range		Skew	Kurtosis
				Actual	Potential		
CDS(Urdu)	25	91.4(14.2)	.91	42-119	25-125	-.6	1.67

Note k= No. of Items, M (SD) =Mean (Standard Deviation),  $\alpha$ =Cronbach's Alpha

The result of this study also revealed that in Urdu this scale is also reliable. (Table 2&3)

**Table 3 The internal consistency of the total scale and subscales of CDS (N=80)**

Measure	No. of Items	Cronbach $\alpha$ value
Total No. of CDS	25	0.91
Child concern	8	0.84
Self-Impact	7	0.83
Caregiver support	5	0.91
Socio- economic Strains	5	0.67

## DISCUSSION

The present study aim was to translate and adapt the Caregiver Difficulties Scale (CDS) in Urdu among caregivers of Cerebral Palsy children. The main reason behind was to assess caregiver Burden in parents who are upbringing CP Children, as well as

to find out scale reliability and validity. Cerebral palsy (CP) is one of those lifelong and long-lasting neurological based physical & intellectual disability that appear early in life. Signs, symptoms and appearances vary among patient to patient, which include spasticity, underprivileged coordination, and muscular weakness. Other associated disorders

include fits, seizures, cognitive/Intellectual issues, sensory deficits, speech & language delays, Chewing & swallowing problems, and many more related issues [14].

The reason of translating this scale is that this scale is specifically constructed for caregivers of cerebral palsy children in English. In original language Cronbach  $\alpha$  of CDS total scale was 0.91. Cronbach  $\alpha$  of 0.68-0.84 in all subscales indicated satisfactory internal consistency within each subscale<sup>10</sup>. The result of this study also revealed that in Urdu this scale is also reliable. Cronbach  $\alpha$  value for the total scale of CDS is 0.91. Cronbach  $\alpha$  of the subscales are .67 to .91 in all subscales, which indicated satisfactory reliability. This scale is translated in other languages also like, it was studied that translation of the caregiver difficulties scale (CDS) into Turkish language revealed its reliability and validity was between 0.83 and 0.90 [11].

Another study reported that CDS is a reliable measure as it is specific for Cerebral Palsy caregivers. CDS was translated in Korean language. The internal reliability of all the items and subdomains of the CDS, is up to the mark. The reliability coefficient (Cronbach's  $\alpha$ ) for all items was 0.89, and the reliability coefficients for each subdomain ranged from 0.687 to 0.849 [15].

Previous research reported that there is an association between caregiver burden and elevated depressive symptoms that affect the quality of life the caregivers of CP children. After proper assessment of the caregiver burden through CDS health professionals can improve the quality of life of the caregivers [16].

## CONCLUSION

The results of the study reveals that Caregiver difficulties Scale is a reliable measure to assess the burden of caregiving among caregivers of Cerebral Palsy children. The findings of this study might be beneficial in rehabilitation of the cerebral palsy children, managing the burden of caregivers can also have a direct impact on the rehabilitation of the disability. It has been a guiding factor for the rehabilitation psychologists to involve the caregivers also in rehabilitation plan.

**Recommendations:** Through identification of caregiver burden and difficulties, a psychosocial rehabilitation-based plan can be prepared by the multidisciplinary rehabilitation specialists that will help to prepare caregivers of CP children for the new roles and coping skills to cater their own psychological issues. It also helps the therapists to access the burden and difficulties of caregivers while parenting cerebral Palsy children. This study could be very effective for rehabilitation professional to develop such psychological rehabilitation

counselling services that address the needs of the caregivers having (CP) disabled children and assist them to cope with and adjust themselves with various social and psychological pressures.

## DECLARATIONS & STATEMENTS

### Author's Contribution

SW and RM: substantial contributions to the conception and design of the study.

SW: acquisition of data for the study.

SW and RM: interpretation of data for the study.

SW and RM: analysis of the data for the study.

SW: drafted the work.

SW and RM: revised it critically for important intellectual content.

SW and RM: final approval of the version to be published and agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. All authors contributed to the article and approved the submitted version.

### Ethical Statement

The Board of Advanced study and Research (BASR) approved the research (IIUI/BASR-16-2021). The study was carried out in Psychology department NIRM (F No: NIRM/1-12-2022) Islamabad Pakistan.

### Consent Statement

Informed consent was obtained from all subjects involved in the study.

### Data Availability Statement

The data presented in this study are available on request from the corresponding author.

### Acknowledgments

None to declare.

### Funding Sources

None to declare.

### Conflicts of Interest

None to declare.

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