

## RESEARCH ARTICLE

# Cross-cultural adaptation, validity, and reliability of the Turkish version of Assistance to Participate Scale

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## Abstract

**Background:** The Assistance to Participate Scale is a questionnaire to evaluate activity participation of children with developmental disabilities. The purpose of this study was to determine the validity and reliability of the Turkish version of the Assistance to Participate Scale.

**Methods:** Ninety-eight mothers' children with developmental disabilities were included in this study. The Assistance to Participate Scale, Pediatric Quality of Life Inventory, and Pediatric Evaluation of Disability Inventory were applied to all subjects. To evaluate reliability, Cronbach's alpha coefficient, minimal detectable change (MDC) with standard error of measurement (SEM), and intraclass correlation coefficient (ICC) for test-retest were used. The relationship between Assistance to Participate Scale, Pediatric Quality of Life Inventory, and Pediatric Evaluation of Disability Inventory was investigated, and exploratory and confirmatory factor analysis were used for construct validity.

**Results:** Cronbach's alpha value of the scale was found .93, demonstrating that this value has excellent internal consistency. Test-retest reliability was found 0.99 (ICC 95% CI [0.995, 0.998]; SEM:0.57, MDC:1.58). For construct validity, the correlations between Assistance to Participate Scale, Pediatric Quality of Life Inventory, and Pediatric Evaluation of Disability Inventory total scores and items were significant ( $p < .001$ ). Factor analysis showed that the questionnaire had unidimensional and the explained variance was 0.84%.

**Conclusions:** The Turkish version of the Assistance to Participate Scale is valid and reliable scale for children with developmental disabilities.

## KEYWORDS

activity participation, disabled children, reliability, validity

## 1 | INTRODUCTION

Provision of rehabilitation services, management strategies, and their outcomes in children with developmental disabilities (CDD) have been extensively discussed in the relevant literature (Lindsay, 2016). Among this body of knowledge, participation of CDD in activities of daily living, play, and leisure is

considered as one of the most important aspects that has direct influence on familial life. According to International Classification of Functioning, Disability and Health (ICF) framework and to recent research, CDD have lower rates of participation in regular activities compared with typically developing children considering intensity and variety (Bourke-Taylor, Law, Howie, & Pallant, 2009).

Traditionally, health care for CDD focuses on early diagnosis, classification, and efforts in diminishing motor impairments such as spasticity, muscle weakness, decreased range of motion, and in managing, associated challenges increasing co-morbidity. However, in the recent years, the aim of the rehabilitation programmes has been shifting from deficit management strategies to proper enhancement of functional success and participation, even in the presence of persisting deficits (Majnemer et al., 2008).

Participation in recreational, play, and leisure activities provides various opportunities for having fun, being with peers, and making friends with other children (Chiarello et al., 2014). In addition, it helps develop a healthy identity and become an active and independent member of the society (Michelsen et al., 2009; Solish, Perry, & Minnes, 2010). Increased participation in play and leisure activities may also have an important effect on adequate and sufficient development in motor and cognitive abilities (Raz-Silbiger et al., 2015). Participation not only contributes positively to the child's physical and social well-being but also increases the quality of life of the family (Bult, Verschuren, Lindeman, Jongmans, & Ketelaar, 2014; Chiarello et al., 2014). Thus, participation is considered as one of the primary aims of the relevant rehabilitation programmes (King et al., 2003; Shikako-Thomas et al., 2012).

Measuring participation of CDD in activities related to daily living, play, and leisure is an important aspect in developing, implementing, and monitoring rehabilitation interventions. Measuring the effectiveness of these interventions, one may also be able to guide the primary caregiver and other family members regarding the level of assistance that CDD require in selected activities. In addition, environmental, personal, and familial factors can be restrictive or incentive for a given activity participation in CDD. Thus, identification of the effects of these factors may provide an optimal approach in determining the current situation of CDD (Michelsen et al., 2009).

Several multipurpose generic tools like Pediatric Evaluation of Disability Inventory (PEDI), Pediatric Quality of Life Inventory (PedsQL), Childhood Health Assessment Questionnaire, and Child Health Questionnaire have been previously developed and cross-culturally adapted into Turkish. These parent-report tools, which evaluate many aspects of quality of life along with activities such as eating, self-care, and social attendance, are commonly used in scientific reports and clinical settings (Singh, Athreya, Fries & Goldsmith 1994; Landgraf, Abetz & Ware 1996; Ozdogan et al., 2001). However, as they are designed to gather information in a broader aspect, they do not focus on a specific and single construct like participation. Besides, they rather took long to complete; thus, they are time-consuming.

The assessments to better understand and describe constrained lives of CDD are common in the literature. Because of the special need and difficulties of CDD in performing daily living activities, ICF was required to extend and International Classification of Functioning, Disability and Health-Children and Youth (ICF-CY) was developed to provide the clinicians a wider perspective about important aspects of activity and participation for CDD. Due to this reason, the researchers cared about ICF-CY framework during assessing activity and participation of CDD. There are many assessment tools for activity and

#### Key messages

- The participation of children with developmental disabilities (CDD) must be measurable.
- Measuring participation of CDD in activities related to play and leisure is an important aspect in implementing and developing rehabilitation interventions.
- The APS-TR is a valid and reliable tool for assessing participation in CDD.

participation of CDD in ICF-CY framework such as Assessment of Life Habits, Preschool Activity Card Sort, Pediatric Activity Card Sort, Children Helping Out: Responsibilities, Expectations and Supports, Children and Adolescent Scale of Participation, Participation in Activities of Daily Living, and Participation and Environment Measure for Children and Youth. These assessment tools had number of items between 15 and 85; however, two of the activity and participation assessments for CDD had less number of items. The number of meaningful ICF-CY concepts linked among these assessments was found 18–123. The percentage of participation was between 31.8 and 88.0 (Chien, Rodger, Copley, & Skorka, 2014).

Assistance to Participate Scale (APS) was designed by Bourke-Taylor et al. (2009) to measure the amount of assistance that a school-aged (5–18 years) child with developmental disabilities requires in order to participate in enjoyable game, leisure, and recreational activities from the perspective of the person who provides the main care-giving activities to the child. It was developed in Victoria, Australia, as a necessity that was raised from a framework that required assessing the impact of care-giving tasks on mothers having a school-age child with developmental disabilities. The construct that APS aims to measure is the amount of assistance that is delivered to a child with developmental disabilities during leisure and play activities (Bourke-Taylor et al., 2009). APS consists of eight items to assess activity and participation of CDD. The scale was examined within the context of ICF-CY in a study. The results showed that the number of meaningful ICF-CY concepts linked was 11 for APS, whereas the percentage of participation items was 75%. APS had higher percentage of participation items with less number of total scale items (Chien et al., 2014). Moreover, Rasch analysis of APS showed good fit to the model, with no misfitting items and good internal consistency (PSI = 0.85; Bourke-Taylor & Pallant, 2013). According to the results of the studies, APS can be used as a useful, practical, and reliable assessment tool for activity and participation of CDD with less number of scale items and within the context of ICF-CY framework.

There are many assessments with Turkish validation to measure quality of life of CDD. But a short and easy to understand assessment needs to evaluate the daily living activities and participation of CDD, specifically. Adaptation of this kind of assessment in Turkish is important to determine activity and participation levels of CDD and the effect of participation levels of CDD on their families in Turkey. For

all these reasons, the aim of this study was to develop the Turkish version of Assistance to Participate Scale (APS-TR) and to examine whether it is a valid and reliable tool for assessing participation in CDD.

## 2 | METHODS

Prior to the initiation of the translation study appropriate permissions were obtained from Prof Helen Bourke-Taylor via email.

### 2.1 | Participants

Ninety-eight mothers having a child diagnosed with neuro-developmental disability were included in the study similar to the original study. All mothers were referred to a University Hospital, Pediatric Neurology Department. Improved consent was obtained from the all subjects.

Inclusion and exclusion criteria were as follows:

1. The mother should be the primary caregiver of a school-aged child (5–18 years old) diagnosed with neuro-developmental disability,
2. Mother should live in the same house with the child diagnosed with neuro-developmental disorder,
3. Mothers who cannot speak Turkish fluently, who have health problems preventing them to complete all the measurements, or who cares than one disabled child were excluded from the study.

### 2.2 | Ethical consideration

This study was supported by Pamukkale University's Ethics Committee (Reference number: 60116787-020/65462). The institutional review boards approved the study, and written informed consent was obtained from the parents of all subjects before enrolment. The study was conducted in accordance with the principles of the Declaration of Helsinki.

### 2.3 | Outcome measures

#### 2.3.1 | Assistance to Participate Scale

APS measures the level of assistance that a school-aged child with a disability needs to participate in game, leisure, and recreational activities at home and in the community, from the perspective of the primary caregiver. APS consists of eight items to assess activity and participation of CDD. It takes 5–10 min to answer the APS by the caregivers. Participants were asked to rate the level of assistance that they typically provide to their child on a 5-point ordinal scale (1 = *Unable to participate*; 2 = *Participates with my assistance at all stages of the activity*; 3 = *Participates after I have set him/her up and help at times*

*during the activity*; 4 = *Participates with my supervision only*; 5 = *Participates independently*). The minimum and maximum scores range between 8 and 40. Lower scores indicate requirement of higher levels of assistance (Bourke-Taylor et al., 2009).

#### 2.3.2 | Pediatric Quality of Life Inventory

PedsQL was developed in 1999 by Varni, Seid, and Rode (1999) and adapted into Turkish (Memik, Agaoglu, Coşkun, Uneri, & Karakaya, 2007). PedsQL is a generic and multidimensional instrument that has 23 items (Physical, Emotional, Social, School, and Psychosocial) evaluating the disability and related problems from the perspective of the primary caregiver. Item scores range from 0 to 100. The scores are calculated as follows: never—100, rarely—75, sometimes—50, frequently—25, and always—0. Consequently, higher score indicates a better health-related quality of life (Memik et al., 2007; Varni et al., 1999). Cronbach's alpha coefficient for the Turkish version of PedsQL (parent report total score) was calculated as.87 by Memik et al. (2007).

#### 2.3.3 | Pediatric Evaluation of Disability Inventory

PEDI was developed in 1992 and adapted into Turkish in 2007 (Haley, Coster, Ludlow, Haltiwanger & Andrellos 1992; Erkin, Elhan, Aybay, Sirzai & Ozel, 2007). The level of caregiver assistance was measured with PEDI as it is a widely used instrument determining the level of disability and caregiver assistance (Ziviani et al., 2001). Items are evaluated on a 6-point Likert scale (0 = *total assistance*, 5 = *independence*). The caregiver assistance scale of PEDI comprises three subdomains: self-care (eight items), mobility (seven items), social function (five items). Each of the subdomains are scored separately. The instrument was previously translated into Turkish and Cronbach's alpha coefficient for the Turkish version of PEDI was reported to be.98 (Erkin et al., 2007).

### 2.4 | Translation and cross-cultural adaptation study

The trans-cultural adaptation process consisted of four phases and was implemented using the guideline developed by Beaton, Bombardier, Guillemin, and Ferraz (2000).

#### 2.4.1 | First phase

The forward translation was conducted by two translators who were fluent in English but their native language was Turkish (T1 and T2). One of the translators was a physiotherapist and aware of the study. The other one was not a health professional and was not informed about the study.

## 2.4.2 | Second phase

The two Turkish translations were unified in a meeting convened among the two translators and two other physiotherapists by reaching a consensus (T-12). Two bilingual translators whose native language was English back translated T-12 version to English (BT1 and BT2). Following that, BT1 and BT2 were sent back to Prof Bourke-Taylor and CanChild for further approval of the translated versions. The pre-final version of the questionnaire was obtained after the second meeting between the translators and the physiotherapists (Appendix I).

## 2.4.3 | Third phase

In order to be sure that the pre-final version still held its linguistic equivalence, a pilot study was undertaken. Thirty mothers who have a child with neuro-developmental disability completed the pre-final version to determine any misunderstandings and problems in the translation process. Acceptability and comprehensibility of the translation were analysed considering the reports obtained as a result of the meetings held by the translators and physiotherapists and the notes provided by the mothers who have completed the pre-final version. Any inquiries related to the idioms and colloquial forms of the items were recorded.

According to these inquiries, several changes were performed during pre-final version development. First, the mothers had confusion about the meaning of eighth item in APS (attending an organized recreational club, ballet, soccer, scouts, etc.) as in Turkish "organized" can be understood as "regularly or planned organization." Therefore, cultural adaptation of this item has been made, and the item becomes more understandable in Turkish. Second, mothers had also some questions about the meaning and content of the third level of assistance that mothers typically provide to their child "3 = Participates after I have set him/her up and help at times during the activity." There is only one word for her/his/it in Turkish, so "my child" was used instead of "him/her."

## 2.4.4 | Fourth phase

Following the pilot testing, APS-TR was administered to 98 mothers. Demographic and clinical data were taken from all mothers during a face-to-face interview.

## 2.5 | Statistical analysis

Continuous variables were presented as means  $\pm$  standard deviations and categorical variables as percentages. The sample size was determined as recommended that the minimum tenfold participants per item was satisfied (Tonga, Gabel, Karayazgan, & Cuesta-Vargas, 2015).

## 2.6 | Reliability

Internal consistency of APS-TR was assessed with Cronbach's alpha coefficient. Cronbach's alpha value was considered excellent for above.80 (Streiner & Norman, 1995). In addition, test-retest reliability was analysed using intra-class correlation coefficient (ICC; one way random). For this purpose, APS-TR was administered to the same participants (98 mothers) 7 days later following the initial evaluation.

## 2.7 | Construct validity

The adequacy of the sample was tested with Kaiser Meyer Olkin Test (KMO) and Sphericity with Bartlett test before exploratory factor analysis was performed. It has been reported that the lower limit of KMO should be 0.50 so that the data cluster cannot be factorized for  $KMO \leq 0.50$  (unfactorability). Based on this information, we determined that factor analysis could be performed for APS-TR.

Spearman correlation coefficients were used in order to test the conformity between APS-TR, PedsQL (parent report total score and physical health summary score), and PEDI (caregiver assistance scale). Interpretation guidelines for  $r$  were provided by Frey, Botan, and Friedman (1991):  $r < .20$  very weak correlation,  $r = .20-.40$  weak correlation,  $r = .41-.70$  moderate correlation,  $r = .71-.90$  strong correlation,  $r > .90$  very strong correlation.

## 3 | RESULTS

Ninety-eight mothers (mean age:  $38.6 \pm 7.0$  years old) having a child with neuro-developmental disability (mean age:  $10.3 \pm 3.9$  years old) were included in this study. Demographic and clinical data related to mothers and their children are presented in Table 1.

The raw scores of APS-TR, related sub dimensions of PEDI and PedsQL were shown in Table 2.

### 3.1 | Reliability

Cronbach's alpha value of the scale was found.93. This value indicates that internal consistency of questionnaire is excellent. Test-retest reliability was found as (ICC) 0.997 (ICC 95% CI [0.995, 0.998]; SEM:0.57; MDC:1.58/at least 1.58 points difference in MDC between test and retest should be accepted as clinically significant). In our results, the floor effect was 5.1%, and the ceiling effect was 13.3%. The results show that there is no floor/ceiling effect.

### 3.2 | Construct validity

Factor analysis of the correlation matrix for APS was determined as suitable as indicated by KMO values (0.84) and Bartlett's Test of Sphericity ( $p < .001$ ). The components recorded eigenvalue exceeding

**TABLE 1** Demographic data related to children and mothers

Mothers		Mean (SD)	Min.–Max.
Age (year)		38.6 (7.0)	23–60
Children		Mean (SD)	Min.–Max.
Age		10.3 (3.9)	5–18
		n	%
Diagnosis	Cerebral palsy	68	68.2
	Duchenne muscular dystrophy	10	10.2
	Brachial plexus injury	2	2.5
	Physical disability	8	8.0
	Hydrocephalus	2	2.5
	Spina bifida	2	2.5
	Autism	1	1.0
	Visually disabled	1	1.0
	Mental retardation	4	4.1

**TABLE 2** The raw scores of the APS-TR, related subdimensions of PEDI, and PedsQL

	Mean (SD)
APS-TR (test)	28.32 (10.38)
APS-TR (retest)	28.14 (10.29)
PEDI (self-care)	19.39 (14.52)
PEDI (mobility)	19.81 (13.70)
PEDI (social function)	15.03 ( 9.38)
PedsQL (physical health summary score)	44.70 ( 29.14)
PedsQL (parent report total score)	51.52 ( 18.99)

Abbreviations: APS, Assistance to Participate Scale; PEDI, Pediatric Evaluation of Disability Inventory; PedsQL, Pediatric Quality of Life Inventory.

1, explained 69.4% of the variance respectively. According to factor analysis, the questionnaire is determined to be unidimensional.

There were positive, moderate, and strong correlations between APS-TR total score, PedsQL (parent report total score and physical health summary score), and the three sub-subdomain scores of the caregiver assistance scale (PEDI; Table 3).

## 4 | DISCUSSION

The aim of this study was to conduct the Turkish cross-cultural adaptation, validity, and reliability study of APS. Our results showed that the APS-TR is a valid and reliable measurement tool for evaluating participation in play and leisure activities in CDD.

It is recommended that the time interval used in reliability studies should change between 2 hours to 2 weeks. The two most important points in determining the time interval are the time lapse to forget the answers given by the respondent and stability of the medical

**TABLE 3** Correlations between APS-TR and related subdimensions of PEDI and PedsQL

	Correlations with APS-TR
PEDI (self-care)	0.762*
PEDI (mobility)	0.694*
PEDI (social function)	0.803*
PedsQL (physical health summary score)	0.636*
PedsQL (parent report total score)	0.628*

Abbreviations: APS, Assistance to Participate Scale; PEDI, Pediatric Evaluation of Disability Inventory; PedsQL, Pediatric Quality of Life Inventory.

\* $p < .001$ .

\*\* $p < .005$  (Spearman correlation coefficient).

condition that is related with the construct that is aimed to be measured (Terwee et al., 2007; Gunaydin et al., 2016). In our study, 7 days of time lapse was provided before introducing the retest to the participants. Our results showed that ICC value of APS-TR was 0.997 (ICC 95% [0.995, 0.998]) which is quite high. This value indicates that the results obtained using APS-TR were stable over time.

In the original version and in another study conducted on typically developing children between the ages of 3 and 8 years old, Cronbach's alpha values were .88 and .76, respectively (Bourke-Taylor et al., 2009; Joyce, Bourke-Taylor, & Wilkes-Gillan, 2017). The internal consistency analysis of APS-TR, Cronbach's alpha coefficient was found as 0.93, which is almost an excellent result. There were no other versions of the questionnaire in other languages as far as to our knowledge. Thus, no comparisons could be made other than the original language studies. Cronbach's alpha values found in this study and the original study may be considered as similar. However, it is interesting that internal consistency was somehow found to be lower in Joyce et al.'s (2017) study. The age and the sample of convenience (typically developing children) may be possible reasons of this drop down. Another reason could be self-selection of recruitment method which was reported as a limitation by the authors.

APS was originally created with two subdomains which are APS—Home alone (1st–4th questions) and APS—Community social (5th–8th questions; Bourke-Taylor et al., 2009). However, the results of the Rasch analysis in 2013 and the validity study in 2017 showed that the questionnaire was in fact unidimensional (Bourke-Taylor & Pallant, 2013). Similarly, the result of the KMO test in our study also indicated that the questionnaire was unidimensional.

As for the construct validity, our analysis showed that expected correlations were achieved with the relevant scales and subdomains of PEDI and PedsQL. Similar results have been attained both in development and the validity studies (Bourke-Taylor et al., 2009; Bourke-Taylor & Pallant, 2013; Joyce et al., 2017).

Application of the APS takes 5–10 min. This was the first study providing a short, practical, and easy-to-understand assessment tool in order to determine only activity and participation levels of CDD in Turkish. We think that this makes our study valuable. However, there are some limitations of the study. First, we did not analyse

responsiveness of the scale. Second, the sample of our study was heterogeneous. We did not contact the study in a particular group. It could be important to consider this limitation to analyse the results of our study.

We advocate that the influential factors like the gender of the primary care giver should be investigated in future clinical studies. In addition, gathering information about environmental factors such as primary and secondary caregivers' occupational and economic level, as well as personal factors such as their physical and mental health status, that may have effects on their perspective of the burden and the way they cope with it would be beneficial.

Our results showed that APS-TR is a valid and reliable measurement tool that can be used to evaluate participation in play and leisure in CDD. We also recommend that APS-TR should further be tested in children with various chronic health conditions that cause altered activity participation.

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#### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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