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Original Article

Psychometric properties of Turkish version of the Life Participation of Parents Scale

Propriedades psicométricas da versão turca de Escala de Participação na Vida dos Pais

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Abstract

Introduction: According to the holistic view of occupational therapy, it is known that caregiving for children with special needs affects their family in various ways. The life participation of parents with a child with special needs are related to the child, the therapy and child-parents adaptation. Therefore, during the caregiving/ occupational therapy process, there is a need for valid and reliable scales to evaluate the life of parents' participation. **Objective:** The aim of this study was to adapt the Life Participation of Parents scale (LPP) into Turkish and to examine its psychometric properties. **Methods:** LPP was culturally adapted via suggested by Beaton et al. One hundred-eighty-six parents of children with disabilities (Age range: 18-55 y/o,154 female) completed the LPP. Exploratory and confirmatory factor analysis (EFA, CFA) was conducted to investigate the factor structure of Turkish version of LPP (LPP-T). Reliability was tested by internal consistency and test–retest reliability. Internal consistency of the instrument was given as Cronbach's alpha. Test–retest reliability was assessed by intraclass correlation coefficient. **Results:** According to the EFA, it was determined that 11 items were collected in a single factor and factor load explained 40,816% of the total variance. According to the CFA, it was seen that the single-dimension scale structure consisting of 11 questions generally fit acceptable in this scale. The LPP-T demonstrated good internal consistency, with Cronbach's alpha of 0.849 for the total scale. The test-retest reliability was good (with ICC of 0.875). **Conclusion:** The LPP-T had good internal consistency and test-retest reliability for parents of children with disabilities. This scale was adapted into Turkish to guide Turkish occupational therapists working in the field of pediatrics in planning interventions to support the life participation of parents.

Keywords: Parenting, Community Participation, Disabled Children, Quality of Life.

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Resumo

Introdução: De acordo com a visão holística da terapia ocupacional, sabe-se que o cuidado à criança com necessidades especiais afeta sua família de diversas formas. A participação na vida dos pais de um filho com necessidades especiais está relacionada com a criança, a terapia e a adaptação pais-filho. Portanto, durante o processo de cuidado/terapia ocupacional, há necessidade de escalas válidas e confiáveis para avaliar a participação dos pais em suas vidas. **Objetivo:** O objetivo deste estudo foi adaptar a escala de Participação na Vida dos Pais (PVP) para o turco e examinar suas propriedades psicométricas. **Métodos:** O PVP foi adaptado culturalmente via sugestão de Beaton et al. Cento e oitenta e seis pais de crianças com deficiência (Faixa etária: 18-55 anos, 154 mulheres) completaram o PVP. A análise fatorial exploratória e confirmatória (AFE, AFC) foi conduzida para investigar a estrutura fatorial do PVP. A confiabilidade foi testada pela consistência interna e confiabilidade teste-reteste. A consistência interna do instrumento foi dada como alfa de Cronbach. A confiabilidade teste-reteste foi avaliada pelo coeficiente de correlação intraclasse. **Resultados:** De acordo com a AFE, foi determinado que 11 itens foram coletados em um único fator e a carga fatorial explicou 40,816% da variância total. De acordo com o AFC, observou-se que a estrutura da escala unidimensional composta por 11 questões geralmente se ajusta de forma aceitável nessa escala. O PVP demonstrou boa consistência interna, com alfa de Cronbach de 0,849 para a escala total. A confiabilidade teste-reteste foi boa (com ICC de 0,875). **Conclusão:** A adaptação turca do PVP apresentou boa consistência interna e confiabilidade teste-reteste para pais de crianças com deficiência. Esta escala foi adaptada para o turco para orientar os terapeutas ocupacionais turcos que trabalham no campo da pediatria no planeamento de intervenções para apoiar a participação dos pais.

Palavras-chave: Responsabilidade Parental, Participação Comunitária, Crianças com Deficiência, Qualidade de vida.

Introduction

Caregiving is a common part of being a parent of a child, but the functional limitations and long-term dependency of the child with special needs transform the parenting role in a completely different way (Murphy et al., 2007; Bornstein, 2001). The daily occupations of parents of child with special needs are shaped around the occupational performance of children (Bradshaw et al., 2019). Parents make particular efforts to manage the child's chronic health problems effectively and to fulfil these occupations in everyday life situations. Care is a complicated process that takes extra time and burdens parenting roles (Çavuşoğlu & Yurtsever, 2021). It is explicitly stated in the literature that in order to increase the participation of the child with special needs, parents limit their participation in their own occupations, roles, and lifestyle (Derguy et al., 2015; Sezer, 2018; Kokorelias et al., 2019; Neri et al., 2016; Quittner et al., 2014). In addition, many studies have shown that caregiving has important psychological, social, financial, and pension-related consequences on parents (Neri et al., 2016; Quittner et al., 2014).

Caregiving does not just mean supporting the child in the home but throughout all settings for all life stages (Bornstein, 2001). It is known that caregiving parents earn less money because they have less job involvement, more sick leave, and less productivity when they go to work (McEvilly et al., 2015). Parents also experience a change in the social environment and are exposed to social limitations (Vlachantoni et al., 2020). They are less likely to participate in many activities, including recreational activities and physical activity, in which the person's well-being is known to be directly related (Haegele et al., 2017; van der Linde et al., 2015). These social/participations limitations that arise during caregiving can be detrimental to a person's physical health and psychological well-being (Khan et al., 2014; Akyurek et al., 2023). What caregivers have to deal with and whether they are able to cope and in which areas they are having difficulties is quite specific, depending on the social and cultural structure of the family (Waldman-Levi et al., 2017). However, what all parents have in common is decreased life participation which means attendance and involvement in activities and quality of life and especially increased stress (Jacobs et al., 2016; Samuel et al., 2018; Akyurek et al., 2023). One of the remarkable results of studies focusing on parent-based rehabilitation approaches in recent years is a significant decrease in the quality of life of families and caregivers due to the decrease in their life participation (Waldman-Levi et al., 2017; Cohen et al., 2015; Collins et al., 2020; Akyurek et al., 2023). In addition, the effects of caregiving on the parents may change as children grow (Harniess et al., 2022; Vinayak et al., 2016).

The holistic perspective of occupational therapy also evaluates parents' values and needs to design interventions that target positive parents' outcomes (Fingerhut, 2005; Rosenbaum et al., 1998; Trute et al., 2007). Literature advice parents-based intervention plans in pediatric clients for holistic approach (Trute et al., 2007). However, there was very limited study or development done on assessment that measure results for clients who are parents. (Dunst et al., 2013; Fingerhut, 2005; Lawlor & Mattingly, 1998; Rosenbaum et al., 1998; Trute et al., 2007; Akyurek et al., 2023). In addition, occupational therapists in pediatric practice focus on the direct intervention of the child (American Occupational Therapy Association, 2002; World Health Organization, 2001), and can make various contributions to the parents. For example, if a child with a physical disability is provided with suitable sitting systems and assisted with the transferring equipment, parents will be less restricted in where they can go with their children, or they may be less likely to injure themselves with the biomechanical principles they have learned. Also, occupational therapy for a child with an eating problem can help parents eat more comfortably with their child. It can even positively affect their quality of life by increasing the opportunity to eat out. According to the examples, it can be thought that occupational therapy can contribute to the adaptation of the family to the occupations necessary for social participation during the caregiving role. (Fingerhut, 2005). However, due to the limited number of scales, it is thought that these examples were obtained only on an observational basis and the studies required for proof are limited.

The Life Participation for Parents scale (LPP) was originally developed in English to assess satisfaction with the efficiency and effectiveness of parental life participation while raising a child with special needs (Fingerhut, 2013). The LPP is designed based on the Occupational Adaptation (OA) reference framework to measure a client's

(parent of a child with disabilities) personal experience of relative mastery (efficiency, effectiveness, and personal satisfaction) in roles and occupations. In the OA reference framework, the term “occupation” is defined as activities of daily life, taking care of themselves and others, working, spending free time, etc., and the term "parent" used to the primary caregiver of a child. In the OA reference framework, the adaptation process between the occupational challenges and the person, the environment, and the occupation in raising children with disabilities results in different adaptation processes depending on the individual characteristics and environmental contexts of the parents (Schkade & Schultz, 1992). To effectively measure life participation, both subjective (emotional or psychological) and objective (physically observable) aspects of performance need to be considered (American Occupational Therapy Association, 2002). Identifying problems is the defining purpose of the LPP. The construct being measured is the degree to which parents are satisfied with the amount and quality of their life participation that might be affected by their child's therapy. The LPP has two specific goals: (1) to provide occupational therapists with descriptive data to aid in the design of parents-centered interventions, and (2) to measure the effectiveness of interventions by determining parent satisfaction with their ability to life participation. LPP can help raise awareness about needs while determining parental life satisfaction (Fingerhut, 2009).

Justification and Objectives

The involvement of a parent with a child with special needs in life is critical for both the child and the parents. Therefore, it is stated that it is important for health professionals working with children with special needs to evaluate how parents' participation in life is affected by using standardized measurement tools. Evaluations to be made in this context will guide the determination of the effect of occupational therapy on the life participation of the caregiver parents and the planning of interventions for them. However, in Turkey, there is a lack of instruments to assess the participation of parents in life, which may result in inadequate approaches for parents. Scales developed in one cultural context and translated for use in another need empirical scrutiny to ensure psychometric soundness. The aim of this study was to translate the Life Participation of Parents scale culturally into Turkish and to adapt it in accordance with the Turkish context and examine its psychometric properties. Therefore, with this study, it is thought that various contributions will be made to the literature regarding clinical practice and research by eliminating the above-mentioned lack.

Methodology

The aim of this study was to translate LPP into Turkish, to make its cultural adaptation and to examine its psychometric properties. In order to do this, the following various steps were followed. This validity study was conducted under the approval of the Ethics Committee of the Hacettepe University Senate regarding medical ethics (No=431-859). Before ethics committee approval, permission was obtained from the developer of the scale to carry out this study (Fingerhut, 2013). The Turkish version of

LPP (LPP-T) was generated through a translation and adaptation procedure, as Beaton et al. (2000) indicated.

Cultural adaptation

As suggested by Beaton et al. (2000), firstly, the original form of the LPP scale was translated into Turkish by two native Turkish speakers with good English language levels who were not informed by context of the scale. Secondly, the two Turkish versions were combined by an expert committee, and cultural adaptations were performed. Thirdly, the draft version was back-translated to English by native speakers who were also not informed by the context. Fourthly, the two back-translated versions were combined, and the pre-final version was sent to the authors with necessary explanations of adaptations by the expert committee. Each item of the LPP was the same as that in the original version. Fifthly, the pre-final form was administered in a pilot group of 35 parents of children with disabilities to evaluate the Turkish version's intelligibility. Then, parents were interviewed on the clarity of each item. In the interviews, 28% of people suggested to change the phrase "significant other" to "partner" to make it culturally fit in Turkish context. There were no other changes made to create a cultural fit. At last, the final form was generated. Data collected in this phase were not included in statistical analyses.

Data collected through the following scales were used for validity and reliability analyses.

Tools

Life Participation of Parent Scale. It is a self-reported scale with 23 items. It was generated by Fingerhut (2009) to measure satisfaction with participation in parental life while raising a child with special needs. Parents/caregivers complete the questionnaire using a 5-point Likert scale. Below each item scored according to the Likert, there is a comment section that is not included in the scoring. The purpose of this commentary section is for clinician occupational therapists to monitor minor changes in the effectiveness of family-centered intervention or to gain additional information when designing their therapies. The questions are worded positively and negatively (2, 4, 6, 8, 10, 11, and 12 are reverse-scored). The time required for parents to complete and for an occupational therapist to score was less than 10 minutes. A lower score indicates more participation problems. The original scale demonstrates high internal consistency with Cronbach's alpha 0.90 (total alpha= 0.90, Efficiency alpha= 0.90, Effectiveness alpha= 0.70) (Fingerhut, 2009).

Short Form-12. Quality of life questionnaires is widely used to assess leisure, employment, and community participation in caregiving parents of children with special needs (Davy et al., 2022). *Short Form-12-TR (SF-12-TR),* consists of a subset of 12 items, which makes it easier to use, from the SF-36® Health Survey. It examines the quality of life through general health status under two headings, mental and physical. It is known that the psychometric properties of the Turkish form of SF-12-TR are similar to the original version; it is valid and reliable (Soysal Gündüz et al., 2021) and also that the SF-12-TR can be used as an alternative to the SF-36-TR in clinical and research settings in Turkey (Soylu & Kütük, 2022).

Participants

In the validity and reliability studies, we decided to include 5 to 10 times the number of items according to the number of applications and ten times the number of items and determined that 230 people should be included in the study (Leung, 2015). The reliability and validity of the LPP-T were carried out by including 230 parents of children with special needs who received occupational therapy services for their children from the pediatrics unit of the Department of Occupational Therapy, Faculty of Health Sciences, Hacettepe University. All parents of children with special needs who were intervened in the Pediatrics Unit of the department were eligible to participate in the study. However, those whose main language was not Turkish and who was caring for an adult or elderly person were excluded. After that, 230 parents selected randomly according to the flipping-a-coin method were informed about the study; volunteers and those who met the study criteria were asked to sign their consent and fill out the LPP-T and Short Form-12 (SF-12) forms. However, the number of participants decreased to 186 due to reasons such as not completing the scale completely (n=24), or withdraw from the study (n=20). The LPP-T was re-administered to one-third of the parents (n=54) with the 14-day interval to assess test/re-test reliability.

Statistical analysis

The statistical analyses were performed using SPSS v.24 and Amos v.18 software. A p-value of <0.05 was accepted as statistically significant for all statistical analyses. The mean and standard deviation (SD) values were also presented. The first of the psychometric analyzes was exploratory factor analysis, and the ''Principal Components Method' was applied as a factor extraction method. Varimax transformation was applied. Expressions over 0.400 were included in the factor load. Confirmatory factor analysis was used to confirm whether the factor structure of LPP-T was the same as it was determined for the original version (Altman et al., 1983). Internal consistency was assessed using Cronbach's alpha. The LPP-T was re-administered by an interview to assess test-retest reliability using the intra-class correlation coefficient (ICC) with a confidence interval of 95%. To analyze the construct validity of LPP-TR, SF-12-TR was used as a gold standard scale. Data were tested for normality by using Shapiro-Wilk's test. The data distribution was normal. Therefore, the relationship between the SF-12-TR and LPP's total scores was examined via Pearson's rho correlation coefficients. In comparing demographic data with LPP-T total score, the Student t test was used for numerical data and one-way ANOVA analysis was used for ordinal data.

Results

Descriptive statistics

All the participants (n=186) were randomly selected from the client's list of the *** University Department of Occupational Therapy, pediatric unit. The gender and age of the parents and the sex, age, and diagnosis of the children were given in Table 1.

Table 1. Participant characteristics.

Gender of Parents	**n=186**	**%**		
Female	154	82.7		
Male	32	17.3		
Sex of children				
Boy	75	40.32		
Girl	111	59.68		
Diagnoses of children				
Neurodevelopmental disorders*	39	21.5		
Cerebral palsy	24	12.9		
Autism spectrum disorder	17	9.13		
Down syndrome	14	7.52		
Other developmental disorders	23	12.36		
			Mean(SD)	**Min-max**
Age of children, year			5.53±3.03	2-16
Age of parents, year			46.90±12.70	33-67
Time since beginning of therapy, year			3.50±2.41	1-10

*Specific learning disabilities and/or attention disorders and hyperactivity disease. SD: standard deviation.

Exploratory factor analysis

The Kaiser-Mayer-Olkin (KMO) value for scale was found to be 0.836. Thus, it was seen that the results of factor analysis to be applied to the data were useful and usable. As a result of the Bartlett Sphericity test, it was concluded that there were significant high correlations between the variables, and the data were suitable for factor analysis (X^2:682,062, sd:55, p<0.001). In the literature, the factor load must be greater than 0.4 (Ferguson & Takane, 1989). The higher the factor load, the better the explanatory power of those items is considered (Tabachnick & Fidell, 2001). As a result of the factor analysis applied for measurements, it was determined that the content validity of 11 items was collected in one factor, and all factor loads were above 0.400. The item numbers of the questions in the original scale, each factor loading of the question item, eigenvalue and explained total variance of this factor were given in Table 2. Item numbers, 1,2,3,4,5,7,8,9,12,21, and 23 were removed from the Turkish version of the scale since they do not fit in the factor structure These questions were mainly about spending time on hygiene needs, spending time with teachers/therapists, and arranging a time for the child with special needs compared to the child with typical development (i.e. 2nd item: *I am able to manage my child's physical and personal hygiene needs*; 9th item: *I spend more of my time arranging and providing social activities for my child, than I would like. (e.g. things to do, people to play with etc.*; 12th item: *I am able to effectively do errands with my child. (e.g. shopping, banking, deliveries)*).

Table 2. Scale factors*.

	Questions	Factor loading	Eigenvalue	Total Variance Explained
LPP-T	Item 18	0.834	4.490	40.816
	Item 17	0.743		
	Item 20	0.739		
	Item 19	0.726		
	Item 15	0.679		
	Item 16	0.594		
	Item 22	0.584		
	Item 14	0.580		
	Item 10	0.521		
	Item 6	0.467		
	Item 13	0.435		

*Items are given in the appendix

Confirmatory factor analysis

The LPP was originally developed by using an Occupational Adaptation (OA) model that had items aiming to describe satisfaction with the efficiency of participation (time spent) and the effectiveness of participation (goal achievement). By using this conceptual model, it was hypothesized that these two aspects of the overall construct of life participation for parents might provide useful subscales, thus providing an impetus for the two-factor model. However, according to the exploratory factor analysis EFA analysis results, the original model could not be adhered to and confirmatory factor analysis (CFA) was performed with the new model.

Confirmatory factor analysis was applied to the data of 186 participants using the IBM SPSS 24 and AMOS 23 program. In the first stage, the CFA model, in which the endogenous variable of single factor and the expressions forming these factors were included as exogenous variables, was created in Figure 1. Accordingly, in order to estimate the parameter values of the endogenous variable, it was applied by assigning a value of 1 to one of the paths drawn from the endogenous variables to the exogenous variables or by assigning a value to the variance of the endogenous variable (usually 1) (Hair et al., 2012).

In the second stage, the maximum likelihood method, frequently used in structural equation models and gives reliable results even when the data was not normally distributed, was used when estimating the model. It aimed to estimate the parameters, including the exogenous variables' errors, the endogenous variables' variances, and the regression coefficients of the paths drawn from the endogenous to exogenous variables. In order to improve the fit indices in scale, a two-way relationship was established between the error terms of the questions *"item 6" and "item 16", "item 18" and "item 20"* which have the highest modification indices value (Figure 1).

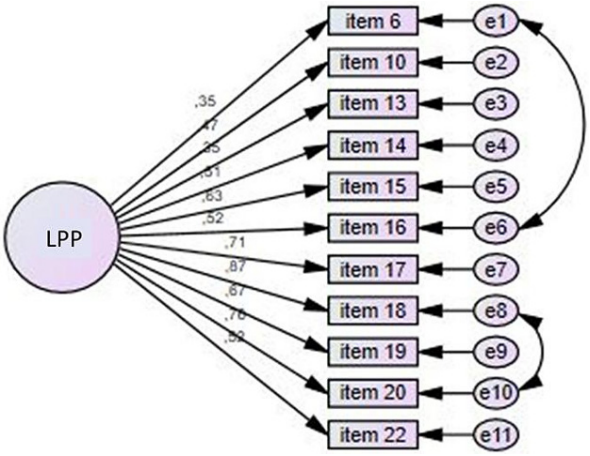

Figure 1. Single-Dimensional 1st Order CFA Model.

At the last stage, fit indices were analyzed for the single-dimensional 1st-degree CFA model (Table 3). According to the analysis, it was seen that the single-dimension measurement structure consisting of 11 questions generally fit acceptable in this scale (see Appendix).

Table 3. Goodness of fit indexes and acceptable value ranges used in the study.

Indexes	Goodness Fit	Acceptable Fit	Results
χ2/df	0≤χ2/df≤3	3≤χ2/df≤4	2.097
GFI	0.95≤GFI≤1	0.85≤GFI≤0.95	0.927
TLI	0.95≤TLI≤1	0.90≤TLI≤0.95	0.906
CFI	0.95≤CFI≤1	0.90≤CFI≤0.95	0.928
RMSEA	0≤RMSEA≤0.05	0.05≤RMSEA≤0.08	0.077
SRMR	0≤SRMR≤0.08	0.05≤SRMR≤0.10	0.052

GFI=Goodness of Fit Index, TLI= The Tucker-Lewis Index; CFI= Comparative Fıt Index, RMSEA= Rout mean squared error of approximation, SRMR= Standardized Root Mean Square Residual.

An acceptable model fit was demonstrated in the χ2/df, GFI, TLI, CFI, RMSEA and SRMR values (Hair et al., 2012; Meydan & Şeşen, 2011; Everett, 2013; Tabachnick et al., 2013). In general, it can be said that the LPP scale is acceptable when looking at the fit indices (GFI>0.85: Anderson & Gerbing, 1984; Cole, 1987; Marsh et al., 1988).

Internal consistency and reliability analysis results

One of the most frequently used criteria during the assessment of scale reliability is Cronbach's alpha, a measure of internal consistency. Cronbach's alpha value was calculated for the scale. This value should be higher than the generally accepted value of 0.70 (Anderson & Gerbing, 1984). Accordingly, if the item-total score correlation coefficient is below 0.30, it is considered that there is a serious problem with these items,

and these items can be removed from the scale. An item-total score correlation coefficient of 0.30 and above is interpreted as acceptable for reliability. However, it is not a stand-alone criterion for eliminating items below this value; the item's effect on Cronbach's alpha coefficient should be evaluated, and a decision should be made (Cole, 1987; Marsh et al., 1988). Therefore, any items were not found below 0.30 in the LPP-T in this study, and it was decided not to remove these items from the scale since any items did not significantly change the Cronbach's alpha value when these items were deleted in the item analysis (Table 4).

Table 4. Scale and sub-dimensional reliability.

	Questions	Item-total Correlation	Cronbach's Alpha if the item is deleted	Cronbach's Alpha
LPP-T	Item 6	0.386	0.847	0.849
	Item 10	0.418	0.845	
	Item 13	0.348	0.850	
	Item 14	0.479	0.841	
	Item 15	0.574	0.833	
	Item 16	0.496	0.840	
	Item 17	0.643	0.827	
	Item 18	0.761	0.818	
	Item 19	0.630	0.828	
	Item 20	0.644	0.828	
	Item 22	0.480	0.841	

As a result of the applied intraclass correlation coefficient (ICC) analysis, the ICC value for the LPP-T scale of 0.875 was found. The reliability coefficient between 0.95-1.00 is accepted as ‘‘excellent”, between 0.85-0.94 as ‘‘high”, between 0.70-0.84 as ‘‘medium”, between 0.0-0.69 as ‘‘unacceptable’ (Şencan, 2005).

As a result of the applied Pearson correlation analysis found a perfect positive correlation between the test and retest measurement for the LPP-T (Şencan, 2005).

No correlation was found between the LPP-T and SF-12-Tr Physical score and SF-12-Tr Mental score (Şencan, 2005).

The total LPP-T score was compared to the variables of the child's diagnosis, age, and time since beginning therapy. No differences were found between groups by the variables of the child's diagnoses, age, and time since beginning therapy. Time in therapy, child's age, and diagnoses did not predict LPP-T scores for the parents of children diagnosed with neurodevelopmental disorders, CP, ASD, Down syndrome, or others.

Discussion

This study aimed to generate the LPP-T, originally developed in English, and to examine the validity and reliability of the LPP-T in parents of children with special needs. Cultural adaptation of the scale was conducted based on internationally accepted methodology under statistical analyses; it was seen that the LPP-T scale was a reliable

and valid tool to assess the participation of parents of children with special needs. With this article, it will be possible to suggest new ways forward by researching about the situation of parents who need special support in life participation by making the use of the scale widespread and by investigating the effectiveness of the interventions to be planned. New understandings can be developed about what are the possible positive life participation outcomes of parents with children with disabilities.

The LPP was culturally adapted to ensure that the concept questioned by each item on the scale was included in Turkish culture, that the examples given in the item were in the Turkish parenting structure, and that there were no expressions that would discriminate while expressing the life experiences of individuals living in Turkish culture. All activities and occupations mentioned in the items were in Turkish and no change was needed in their translation or cultural adaptation. However, the word "significant other" in Article 17 is a person with whom someone has an established romantic or sexual relationship with or without marriage, which can bring shame to the person asked with direct translation in Turkish culture. It was also a concern for the authors that the participants said no to avoid embarrassment instead of focusing on the main topic. Based on the feedback from interviews with pilot group, the expert committee recommended using the equivalent of the word partner.

Confirmatory factor analysis (CFA) showed that the items translated and adapted into Turkish were not in accordance with the original conceptual framework of the LPP-T, and consequently, it was determined which questions were problematic by looking at the exploratory factor analysis. As a result of the exploratory factor analysis (EFA) applied to the scale, it was determined that the content validity of 11 items was collected in a single factor, and all factor loads were above 0.400. According to the EFA, the original model could not be adhered to, and CFA analysis was performed with the new model. According to the CFA result, it was seen that the single-dimension scale structure consisting of 11 questions generally fit acceptable in this scale. It was determined during the pre-test that some of the questions were not found to apply to Turkish culture, and some were not perceived as a problem. Although they were not removed at the first stage in order to adhere to the original scale, they had to be removed according to the factor analyses.

It is known that parenting changes life participation due to changes in the organization of living style regarding age and whether the child has a diagnosis (Vlachantoni et al., 2020; Collins et al., 2020; Cohen et al., 2015). Those changes can be observed in the psychosocial factors of families, such as stress, anxiety, and well-being (Alaee et al., 2015). In the development study of LPP, authors examined the correlation between life participation scores and stress index scores of families. The LPP scores of families were found to be moderately related to Parenting Stress Index-Short Form results regardless of the age, diagnosis, and time in therapy (Fingerhut, 2013). There were studies on the well-being and quality of life of caregiving parents in the literature, and it was generally associated with emotional and psychological factors such as parents' anxiety and the child's complex disability situations (Alaee et al., 2015; Armstrong et al., 2005; Leung & Li-Tsang, 2003; Williams et al., 2003). This moderate relationship between stress and participation in the development study (Fingerhut, 2013) prompted the authors to examine the relationship between quality of life and participation of parents. Also, in our study, the relationship between life participation and quality of life was examined in order to verify construct validity. However, no relationship was found. This situation was

thought to be due to the fact that the children of the participants were diagnosed with specific learning difficulties or attention deficit and hyperactivity disorder in childhood, when the general condition of the child was good. In addition, the ages of children and parents or diagnoses of children did not correlate with the score of the LPP-T in accordance with the given literature. Moreover, no relation between the LPP-T score and the time interval since the beginning of the therapy was observed. Thus, it was understood that LPP-T measures life participation of parents independent of age (for the 2-16 age range), diagnosis and time interval since the beginning of the therapy.

The included participant profile and methodology were the strengths of this study. In the adaptation process, no question was added or discarded regarding cultural appropriateness. As participants, mothers and fathers of children with many different diagnostic groups were included in this study. The inclusion of parents of children from different diagnostic groups (Cavkaytar, 2017; Col, 2015) in this study is another strength of the study in terms of the characteristics of the scale (Karahan & İslam, 2013; Ozturk et al., 2017).

There were also limitations of the study. It is recommended that a validity study should have a participant number of five to ten times of item numbers. Although this study has more than five times of item numbers, larger participant numbers could generate better and stronger results. In addition, the children of the families participating in the study had various diagnoses. Although this allows the scale to be used for many different diagnosis groups, it should be kept in mind that the conditions affecting the family involvement of children in each diagnosis group may differ and each item may have been interpreted in different ways by the participants. Also, the participants were recruited from a single center. Although many clients from various socioeconomic and sociocultural backgrounds apply to this center located in the capital, it is difficult to generalize the results to the whole of Turkish culture.

Conclusion

Lastly, LPP-T is a valid and reliable tool to assess the life participation of parents of children with special needs. In addition to having a high level of validity and reliability, the scale will also be a pioneer because, up to our knowledge, it is the first scale to evaluate the life participation of parents in the Turkish language. By widely utilizing the scale, conducting research on the circumstances of parents who require special assistance in life participation, and examining the efficacy of the intended applications, it will be possible to offer new directions. Future studies may use this instrument to determine barriers to life participation by parents of children with disabilities. Further studies in large samples are needed to evaluate the other factors related to the life participation of parents of children with disabilities. Moreover, we also believe that the number of studies that will be planned for parent-centered approaches will increase. Such studies will enable policy-makers and researchers to better understand the circumstances and quality of life of parents of children with disabilities.

References

Akyurek, G., Gurlek, S., Kaya-Ozturk, L., & Bumin, G. (2023). The effect of parent-based occupational therapy on parents of children with cerebral palsy. *International Journal of Therapy and Rehabilitation*, *30*(1), 1-12.

Alaee, N., Shahboulaghi, F. M., Khankeh, H., & Mohammad Khan Kermanshahi, S. (2015). Psychosocial challenges for parents of children with cerebral palsy: A qualitative study. *Journal of Child and Family Studies*, *24*(7), 2147-2154.

Altman, D. G., Gore, S. M., Gardner, M. J., & Pocock, S. J. (1983). Statistical guidelines for contributors to medical journals. *British Medical Journal (Clinical Research Ed.)*, *286*(6376), 1489-1493.

American Occupational Therapy Association - AOTA. (2002). Occupational therapy practice framework. *The American Journal of Occupational Therapy*, *56*(6), 609-639.

Anderson, J. C., & Gerbing, D. W. (1984). The effect of sampling error on convergence, improper solutions, and goodness-of-fit indices for maximum likelihood confirmatory factor analysis. *Psychometrika*, *49*(2), 155-173.

Armstrong, M. I., Birnie-Lefcovitch, S., & Ungar, M. T. (2005). Pathways between social support, family well being, quality of parenting, and child resilience: what we know. *Journal of Child and Family Studies*, *14*, 269-281.

Beaton, D. E., Bombardier, C., Guillemin, F., & Ferraz, M. B. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine*, *25*(24), 3186-3191.

Bornstein, M. H. (2001). Parenting: science and practice. *Parenting*, *1*(1-2), 1-4.

Bradshaw, S., Bem, D., Shaw, K., Taylor, B., Chiswell, C., Salama, M., Bassett, E., Kaur, G., & Cummins, C. (2019). Improving health, wellbeing and parenting skills in parents of children with special health care needs and medical complexity - a scoping review. *BMC Pediatrics*, *19*(1), 1-11.

Cavkaytar, A. (2017). Özel eğitime gereksinim duyan çocuklar ve özel eğitim. *Pegem Atıf İndeksi*, 3-29.

Çavuşoğlu, E., & Yurtsever, S. (2021). The relationship between health anxiety levels and healthy lifestyle behaviors of family caregivers of cancer patients receiving outpatient chemotherapy. *Journal of Basic and Clinical Health Sciences*, *6*(2), 143-151.

Cohen, S. A., Cook, S., Kelley, L., Sando, T., & Bell, A. E. (2015). Psychosocial factors of caregiver burden in child caregivers: results from the new national study of caregiving. *Health and Quality of Life Outcomes*, *13*, 1-6.

Col, G. (2015). *Özel gereksinimi olan çocukların boş zaman aktivitelerine katılımını etkileyen faktörler* (Yayımlanmamış Yüksek Lisans Tezi). Hacettepe Üniversitesi, Sağlık Bilimleri Enstitüsü, Ankara.

Cole, D. A. (1987). Utility of confirmatory factor analysis in test validation research. *Journal of Consulting and Clinical Psychology*, *55*(4), 584-594.

Collins, A., Burchell, J., Remedios, C., & Thomas, K. (2020). Describing the psychosocial profile and unmet support needs of parents caring for a child with a life-limiting condition: a cross-sectional study of caregiver-reported outcomes. *Palliative Medicine*, *34*(3), 358-366.

Davy, G., Unwin, K. L., Barbaro, J., & Dissanayake, C. (2022). Leisure, employment, community participation and quality of life in caregivers of autistic children: a scoping review. *Autism*, *26*(8), 1916-1930.

Derguy, C., Michel, G., M'bailara, K., Roux, S., & Bouvard, M. (2015). Assessing needs in parents of children with autism spectrum disorder: A crucial preliminary step to target relevant issues for support programs. *Journal of Intellectual & Developmental Disability*, *40*(2), 156-166.

Dunst, C. J., Trivette, C. M., Prior, J., Hamby, D. W., & Embler, D. (2013). *Parents' Judgments of the Acceptability and Importance of Socially Interactive Robots for Intervening with Young Children with Disabilities. Social Robots Research Reports* (No. 1). Asheville: Orelena Hawks Puckett Institute.

Everett, J. A. (2013). The 12 item Social and Economic Conservatism Scale (SECS). *PLoS One*, *8*(12), 1-11.

Ferguson, F., & Takane, Y. (1989). *Statistical analysis in psychology and education.* New York: McGraw Hill Book Company.

Fingerhut, P. E. (2005). *The impact of caring for children with special needs on the ability of parents/caregivers to engage in occupations to support participation* (Doctoral thesis). Texas Woman's University, Denton.

Fingerhut, P. E. (2009). Measuring outcomes of family-centered intervention: development of the Life Participation for Parents (LPP). *Physical & Occupational Therapy in Pediatrics*, *29*(2), 113-128.

Fingerhut, P. E. (2013). Life Participation for Parents: a tool for family-centered occupational therapy. *The American Journal of Occupational Therapy*, *67*(1), 37-44.

Haegele, J. A., Lee, J., & Chang, S. H. (2017). Physical Activity of Parents of Children with Autism Spectrum Disorder. *International Journal of Disability Development and Education*, *64*(4), 368-377.

Hair, J. F., Sarstedt, M., Ringle, C. M., & Mena, J. A. (2012). An assessment of the use of partial least squares structural equation modeling in marketing research. *Journal of the Academy of Marketing Science*, *40*(3), 414-433.

Harniess, P. A., Gibbs, D., Bezemer, J., & Purna Basu, A. (2022). Parental engagement in early intervention for infants with cerebral palsy-A realist synthesis. *Child: Care, Health and Development*, *48*(3), 359-377.

Jacobs, M., Woolfson, L. M., & Hunter, S. C. (2016). Attributions of stability, control and responsibility: how parents of children with intellectual disabilities view their child's problematic behaviour and its causes. *Journal of Applied Research in Intellectual Disabilities*, *29*(1), 58-70.

Karahan, A. Y., & İslam, S. (2013). Fiziksel engelli çocuk ve yaşlı hastalara bakım verme yükü üzerine bir karşılaştırma çalışması. *Clinical and Experimental Health Sciences*, *3*(Suppl.1), S1-S7.

Khan, A. A., Ahmad, K., Ayaz, S. B., Ayyub, A., & Akhlaq, U. (2014). Cerebral palsy in Pakistani children: a hospital based survey. *Cukurova Medical Journal*, *39*(4), 705-711.

Kokorelias, K. M., Gignac, M. A. M., Naglie, G., & Cameron, J. I. (2019). Towards a universal model of family centered care: a scoping review. *BMC Health Services Research*, *19*(1), 1-11.

Lawlor, M. C., & Mattingly, C. F. (1998). The complexities embedded in family-centered care. *The American Journal of Occupational Therapy*, *52*(4), 259-267.

Leung, C. Y. S., & Li-Tsang, C. W. P. (2003). Quality of life of parents who have children with disabilities. *Hong Kong Journal of Occupational Therapy*, *13*(1), 19-24.

Leung, L. (2015). Validity, reliability, and generalizability in qualitative research. *Journal of Family Medicine and Primary Care*, *4*(3), 324-327.

Marsh, H. W., Balla, J. R., & McDonald, R. P. (1988). Goodness-of-fit indexes in confirmatory factor analysis: the effect of sample size. *Psychological Bulletin*, *103*(3), 391-410.

McEvilly, M., Wicks, S., & Dalman, C. (2015). Sick leave and work participation among parents of children with autism spectrum disorder in the Stockholm youth cohort: a register linkage study in Stockholm, Sweden. *Journal of Autism and Developmental Disorders*, *45*(7), 2157-2167.

Meydan, C. H., & Şeşen, H. (2011). *Yapısal eşitlik modellemesi AMOS uygulamaları.* Turquia: Detay Yayıncılık.

Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: caregiver perspectives. *Child: Care, Health and Development*, *33*(2), 180-187.

Neri, L., Lucidi, V., Catastini, P., Colombo, C., & LINFA Study Group (2016). Caregiver burden and vocational participation among parents of adolescents with CF. *Pediatric Pulmonology*, *51*(3), 243-252.

Ozturk, Y. E., Senturk, Ş., & Macit, Y. (2017). Evde Bakım Hizmeti Alan Engelli Bireye Sahip Ailelerin Bakım verme yüklerinin Belirlenmesi: amasya Örneği. *Türkiye Sosyal Hizmet Araştırmaları Dergisi*, *1*(1), 48-67.

Quittner, A. L., Goldbeck, L., Abbott, J., Duff, A., Lambrecht, P., Solé, A., Tibosch, M. M., Bergsten Brucefors, A., Yüksel, H., Catastini, P., Blackwell, L., & Barker, D. (2014). Prevalence of depression and anxiety in patients with cystic fibrosis and parent caregivers: results of The International Depression Epidemiological Study across nine countries. *Thorax*, *69*(12), 1090-1097.

Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centred service: a conceptual framework and research review. *Physical & Occupational Therapy in Pediatrics*, *18*(1), 1-20.

Samuel, P. S., Tarraf, W., & Marsack, C. (2018). Family Quality of Life Survey (FQOLS-2006): evaluation of internal consistency, construct, and criterion validity for socioeconomically disadvantaged families. *Physical & Occupational Therapy in Pediatrics*, *38*(1), 46-63.

Schkade, J. K., & Schultz, S. (1992). Occupational adaptation: toward a holistic approach for contemporary practice, Part 1. *The American Journal of Occupational Therapy*, *46*(9), 829-837.

Şencan, H. (2005). *Sosyal ve Davranışsal Ölçümler Güvenilirlik ve Geçerlilik.* Ankara: Seçkin Yayıncılık.

Sezer, K. Ş. (2018). *Engelli Çocukların Annelerinin Aktivite Performansının İncelenmesi* (Yüksek Lisans Tezi). Hacettepe Üniversitesi, Sağlık Bilimleri Enstitüsü, Ankara.

Soylu, C., & Kütük, B. (2022). Reliability and Validity of the Turkish Version of SF-12 Health Survey. *Türk Psikiyatri Dergisi*, *33*(2), 108-117.

Soysal Gündüz, Ö., Mutlu, S., Aslan Basli, A., Gül, C., Akgül, Ö., Yilmaz, E., & Aydemir, Ö. (2021). Validation of the Turkish Form of Short Form-12 health survey version 2 (SF-12v2). *Archives of Rheumatology*, *36*(2), 280-286.

Tabachnick, B. G., & Fidell, L. S. (2001). *Using multivariate statistics.* Boston: Allyn and Bacon.

Tabachnick, B. G., Fidell, L. S., & Ullman, J. B. (2013). *Using multivariate statistics.* Boston: Pearson.

Trute, B., Hiebert-Murphy, D., & Levine, K. (2007). Parental appraisal of the family impact of childhood developmental disability: times of sadness and times of joy. *Journal of Intellectual & Developmental Disability*, *32*(1), 1-9.

van der Linde, B. W., van Netten, J. J., Otten, E., Postema, K., Geuze, R. H., & Schoemaker, M. M. (2015). A systematic review of instruments for assessment of capacity in activities of daily living in children with developmental co-ordination disorder. *Child: Care, Health and Development*, *41*(1), 23-34.

Vinayak, S., Dhanoa, S. K., & Vinayak, R. (2016). Relationship of hopelessness, depression and quality of life in mothers of persons with disabilities. *International Journal of Innovation and Applied Studies*, *17*(1), 306-311.

Vlachantoni, A., Feng, Z., Wang, N., & Evandrou, M. (2020). Social participation and health outcomes among caregivers and noncaregivers in Great Britain. *Journal of Applied Gerontology*, *39*(12), 1313-1322.

Waldman-Levi, A., Hirsch, I., Gutwillig, G., & Parush, S. (2017). Psychometric properties of the Parents as Partners in Intervention (PAPI) Questionnaires. *The American Journal of Occupational Therapy*, *71*(2), 1-8.

Williams, J., Steel, C., Sharp, G. B., DelosReyes, E., Phillips, T., Bates, S., Lange, B., & Griebel, M. L. (2003). Parental anxiety and quality of life in children with epilepsy. *Epilepsy & Behavior*, *4*(5), 483-486.

World Health Organization - WHO. (2001). *The World health report : 2001 : Mental health : new understanding, new hope.* Geneva: World Health Organization.

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Appendix. **Life Participation for Parents-Turkish* (LPP) ® (2023).**

First developed by Patricia E. Fingerhut, OTR, PhD.

Parent's Name _____ ***Child's Name*** _____

Quality therapy needs to be family-centered. Raising children with special needs affects all family members. This questionnaire addresses many activities of a parent/caregiver that may be affected by raising a child with special needs.

Instructions: Read the questions and think how this aspect of your life is affected by raising a child with special needs. Circle the response that most closely describes how you feel about the statement. Explain how these activities are difficult on the lines labeled comments below. If the question does not apply to you circle not applicable.

Strongly Agree	**Agree**	**Both Agree and Disagree**	**Disagree**	**Strongly Disagree**	***Not Applicable***
1	**2**	**3**	**4**	**5**	**6**

1. I am able to meet my child's emotional needs.

Strongly Agree	**Agree**	**Both Agree and Disagree**	**Disagree**	**Strongly Disagree**	***Not Applicable***

Comments:

2. I am good at providing for my child's social activities.

Strongly Agree	**Agree**	**Both Agree and Disagree**	**Disagree**	**Strongly Disagree**	***Not Applicable***

Comments:

3. Having a child with special needs has interfered with my ability to hold a job or pursue education.

Strongly Agree	**Agree**	**Both Agree and Disagree**	**Disagree**	**Strongly Disagree**	***Not Applicable***

Comments:

4. Financial issues related to my child's special needs are a source of stress for our family.

Strongly Agree	**Agree**	**Both Agree and Disagree**	**Disagree**	**Strongly Disagree**	***Not Applicable***

Comments:

5. Having a child with special needs has restricted my ability to spend time with my friends and family as often as I would like to.

Strongly Agree	**Agree**	**Both Agreeand Disagree**	**Disagree**	**Strongly Disagree**	***Not Applicable***

Comments:

6. Spending time with my friends and family with my child present is stressful.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	*Not Applicable*

Comments:

7. Having a child with special needs restricts the time I would like to spend with my spouse / partner.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	*Not Applicable*

Comments:

8. Having a child with special needs restricts the time I would like to spend with my other children.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	*Not Applicable*

Comments:

9. Having a child with special needs affects my ability to be involved in community activities as often as I would like. (e.g. religious services, charitable organizations, political or community organizations).

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	*Not Applicable*

Comments:

10. Having a child with special needs has affected my health.

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	*Not Applicable*

Comments:

11. Having a child with special needs affects my opportunities to engage in personal activities. (e.g. hobbies, sports, leisure activities).

Strongly Agree	Agree	Both Agree and Disagree	Disagree	Strongly Disagree	*Not Applicable*

Comments:

*Old Item 6 is new Item 1; Item 10 is Item 2; Item 13 is Item 3; Item 14 is Item 4; Item 15 is Item 5; Item 16 is Item 6; Item 17 is Item 7; Item 18 is Item 8; Item 19 is Item 9; Item 10 is Item 20; Item 22 is Item 11.