

The validity and reliability of the Turkish version of the "parental satisfaction with caregiving for children with developmental disabilities" scale

 Hicran Dogru,  Ali Cakir

Department of Child and Adolescent Psychiatry, Ataturk University Hospital, Erzurum, Turkey

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Abstract

Aim: Parents of children with special needs face many difficulties. Additional support may be required for parents who are not satisfied with their disabled child's care. This study aimed to develop the Turkish validity and reliability study of "parental satisfaction with caregiving for children with developmental disabilities", which is evaluated the satisfaction of the parent who gives the care child with a special need.

Materials and Methods: This study included one hundred forty-seven parents, who gave care of children with intellectual disability and autism spectrum disorder. Detailed information gave to participants and their informed consent was obtained. Student t, Mann-Whitney U, Anova and Kruskal Wallis tests were used for statistical evaluation.

Results: The coefficient of Cronbach Alpha was 0.848 and that had a high degree of reliability. The coefficient of Cronbach Alpha of the satisfaction with the child was 0.812 and personal satisfaction was 0.784. In the analysis, KMO value was 0.795; Bartlett's value was also determined as 580.692, which was found statistically significant ($p < 0.00$).

Conclusion: This scale is expected to help researchers identify factors associated with parents' satisfaction with care and also identify factors that make the care process a positive experience for parents. Clinicians and caregivers can use this scale to determine whether parents with children with behavioral problems need additional support.

Keywords: Caring parent; children with special needs; parental satisfaction

INTRODUCTION

Caring for children with special needs is a struggle that can have both positive and negative effects on parents (1,2). Parents' satisfaction with the care of children with special needs is an important determinant for the general health quality of children. Therefore, the support services provided to the children should increase the satisfaction of the parents and at the same time be directed towards the needs and expectations of the parents (3).

Studies evaluating the parents of children with special needs have generally focused on mothers, as mothers have a more active role in the care, upbringing, and education of children than fathers and other family members. Studies about fathers on this subject are rather limited (4-6).

Recently, there has been increasing interest in investigating the impact of having children with special needs on parents in low- and middle-income countries where support services are not sufficiently developed.

Understanding the parents, ideas and perspectives of children with special needs will be important in addressing the special needs of children and parents (7). Although the challenging aspects of the child-rearing process with special needs are expressed more, Taunt et al. As noted by (2002), there are also stories from parents and other family members who show that positive inferences can be drawn from this process (8,9). Consequently, this process can be a critical step in the formation of parental resilience over time. The positive and negative effects of this process on parents were examined in a study and it was shown that these effects were closely related to cultural values (10). Cultural values are thought to play an important role in how parents perceive developmental disabilities and ultimately affect parents' responses to childcare. Having a child with special needs is one of the biggest challenges parents face in some cultures (11). For example, in some eastern cultures, it is known that mothers who have children with special needs generally blame themselves for the current situation (12). Parents

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Corresponding Author: Hicran Dogru, Department of Child and Adolescent Psychiatry, Ataturk University Hospital, Erzurum, Turkey

E-mail: hicran_ktekin@yahoo.com

who displayed a negative attitude towards their children with special needs reported that they believed there was a relationship between the current state of their child and the sins they committed in the past (13,14). Parents' personal attitude is a key role in their approach to children with special needs, and parents can adopt different attitudes towards their children and their impact on their own lives (15). Also, recent studies show that parents' attitudes affect children's physical and psychosocial well-being (16). Kuhn et al. (2006) investigated the relationships between maternal self-efficacy and parenting cognitions and parents' thoughts, attitudes and beliefs about the parenting of Spectrum Disorder (ASD) and found that the attitudes of caregivers were affected by their own upbringing, parenting experiences and interactions with children (17).

To sum up briefly, when the current literature on the effect of caregiving for a child with special needs is looked through, it is seen that caregiving parents had a very low level of satisfaction with caregiving, but caregiving has also been reported to have positive effects on some parents. In addition, parents reported that they act and make a sacrifice in a way that will make the child with special needs happy, increase the child's self-confidence, and maximize the child's potential (18-20). Parental satisfaction can be considered as an important factor in the general quality of life of families with children with special needs. Currently, in most countries, there are very limited studies on children's caregiving with special needs and parental satisfaction. In this study, it was aimed to adapt a scale that Turkish clinicians and service providers can use to describe the satisfaction levels of parents with special needs children and their personal feelings about the caregiving process and to test the validity and reliability of the scale.

MATERIALS and METHODS

This study is a methodological study and was carried out in the Department of Child and Adolescent Psychiatry in Atatürk University Hospital between January-March 2020. Ethical approval was obtained from Ataturk University Hospital with the code number B.30.2.ATA.0.01.00 / 238 for this study. Children who were diagnosed with autism spectrum disorder and intellectual disability according to DSM-5 diagnostic criteria and who had these diagnoses for at least one year were included to the study randomly. The inclusion criteria for the patients were as follows: having diagnosed with autism spectrum disorder according to DSM-5, having diagnosed with intellectual disability according to DSM-5, having this diagnosis for at least a year and not having any accompanying chronic physical or medical illness. The sample of this study was generally composed of children with special needs who applied for a committee report to the outpatient clinic.

The sample volume has been determined according to the validity and reliability studies in the literature, and the literature suggests that the number of participants should be reached 10 times the number of items indicated (21).

Thus, the number of participants required for the 14-item reliability and validity study was aimed to be at least 140. The sample of the methodological study consists of parents with 147 special needs children who applied to a department of child and adolescent psychiatry outpatient clinic in a university hospital. Parents of 160 children with special needs who were diagnosed with ASD and Intellectual Disability according to DSM-5 diagnostic criteria between the ages of 1-18 were selected through simple random sampling and a detailed examination of the study was performed and informed consent was obtained. Participants were asked to fill the scale of "Parental Satisfaction with Caregiving for Children with Developmental Disabilities", in which the satisfaction of the caregiving of the child with special needs and the personal feelings that they had in the process was evaluated. 13 of the parents were excluded from the study because they filled the scale form incompletely.

The alpha coefficient method developed by Cronbach (1951) was used to carry out the validity and reliability study of the scale. The total variance average of the 14 items in the scale is proportional to the general variance and the weighted standard average of change is taken into account. It is an appropriate consistency method to use due to the scoring method of the scale. Concurrent Validity method was used for validity.

Material

This scale called "Parental Satisfaction with Caregiving for Children with Developmental Disabilities" was developed by Samadi et al. in 2018 to be used by clinical and service providers in order to determine the satisfaction of the caregiving parent of children with special needs, the areas they need support, and to evaluate the effect of family-based interventions on parents' satisfaction (22). This scale which was developed in the thesis (19) titled "The impact on Iranian parents who have children with an Autism Spectrum Disorder (ASD)" was planned based on the study by Hastings & Taunt (18). As a result, it is accepted that the scale is understandable by parents who have children with special needs (15).

The scale was translated into the target language independently by two child and adolescent psychiatrist who are fluent in both languages. The scale consists of 14 items. Each item is a five-item likert ranging from "strongly agree" (score 1), "agree" (score 2), "not sure" (score 3), "disagree" (score 4), and "strongly disagree" (score 5). Along with the scale, the demographic information of the parents and children was also questioned. While the first seven items of the scale were examining satisfaction with caring for a child with special needs, the last seven items examined the parents' personal feelings in the process. A higher score indicates a lower less satisfaction. The number of items per participant was calculated as 10.6.

Data Analysis

The information from the questionnaires was analyzed using the Statistical Package for Social Sciences (SPSS) version 24 (IBM, Armonk, NY, USA). The arithmetic mean \pm standard deviation value was given as descriptive

statistics. The reliability findings of the scale were examined with the internal consistency coefficient, two half-test validity and Cronbach alpha value. Student t, Mann-Whitney U, Anova and Kruskal Wallis tests were used to compare numerical data between categorical groups. The statistically significant value was accepted as $p < 0.05$.

RESULTS

Sociodemographic Characteristics of the Sample

A total of 147 parents were included in the study. The average age of the parents was 38.1 ± 7.8 , their proximity to the children was as follows; 54.4% ($n = 80$) were mothers and 45.6% ($n = 67$) were fathers. While 85% of the parents ($n = 125$) did not have a chronic disease, 13.6% ($n = 21$) had a physical disease and 1.4% ($n = 2$) had a psychiatric disease. While 65.2% of the parents had an income level below the minimum wage, 34.4% had an income level above the minimum wage. 64.1% of the participants lived in the city center, 24.1% in the district and 11.7% in the village. The average education year that the parents had was 7.6 ± 4 . The average age of children with special needs was 8.5 ± 4.1 , 76.7% had a diagnosis of intellectual disability, while 23.3% had a diagnosis of ASD. The average number of siblings the children had was 3.2 ± 1.5 .

Statistics Regarding the Care-Giving Satisfaction Scale of the Parents of a Child with Developmental Disabilities

The first seven items of the scale, which has two sub-dimensions, score the satisfaction with caring for a child with special needs. The scale's satisfaction subscale score mean was 9.6 ± 3.6 . The statements about satisfaction part were as follows: My child gives me love and affection,

my child gives me a new or increased sense of purpose in life, Having a child has led me to develop new skills and abilities etc.

The last 7 items of the scale score the personal feelings experienced by the parents during the caregiving process. The average score of the personal feelings subscale of the scale was 10.3 ± 3.9 . The statements about this section were as follows: My child has strengthened our family and/or marriage, I make the most of each day; live life at a slower pace, My social and community networks have expanded etc.

The total mean score of the scale was 20 ± 6.5 . A linear correlation was found between satisfaction subscale scores and personal feelings subscale scores ($r = 0.588$ $p < 0.001$). For the reliability test of the scale used in our study, the total Cronbach alpha coefficients of each basic dimension and sum of items were examined. Both dimensions and sum of items were found to be higher than the conventionally accepted value, and the results were consistent with the "highly reliable" scores.

The Cronbach alpha value of the Turkish version of the scale was 0.848. While the Cronbach alpha value of the first seven items evaluating the satisfaction of parents in providing care to the child was 0.812, the Cronbach alpha value of the seven items evaluating personal feelings was 0.784. Detailed Cronbach Alpha Values of All Items were shown in Table 1.

In order to test the equivalent half's reliability, the scale was divided into two as odd-numbered items and even-numbered items, and the relationship between these two forms was examined.

Table 1. Detailed Cronbach Alpha Values of All Items

Item Number	Mean	Std	Scale average (if item is deleted)	Scale-Variance (if item is deleted)	Adjusted items-Total correlation	Cronbach'sAlpha (if item is deleted)
1	1.2721	0.65749	18.7347	38.498	0.506	0.838
2	1.3333	0.66655	18.6735	38.838	0.456	0.84
3	1.2993	0.68661	18.7075	38.729	0.452	0.84
4	1.2517	0.68089	18.7551	38.104	0.535	0.836
5	1.3061	0.6369	18.7007	38.430	0.535	0.837
6	1.7279	0.97614	18.2789	35.874	0.533	0.836
7	1.4762	0.85475	18.5306	37.004	0.512	0.837
8	1.6395	1.00646	18.3673	35.974	0.503	0.838
9	1.2585	0.62030	18.7483	39.423	0.418	0.842
10	1.3537	0.77462	18.6531	38.488	0.413	0.842
11	1.2313	0.52431	18.7755	39.956	0.427	0.842
12	1.5102	0.78833	18.4966	38.498	0.403	0.843
13	1.517	0.92421	18.4898	34.649	0.695	0.824
14	1.8299	1.2296	18.1769	33.434	0.571	0.836

Parental Satisfaction with Caregiving for Children with Developmental Disabilities Scale

The correlation coefficient between the two forms was 0.79 and the total reliability coefficient of the test was calculated as 0.88 using the Spearman-Brown formula. Explanatory Factor Analysis was applied to test the construct validity of the scale. As a result of the factor analysis, it was determined that the Kaiser-Meyer-Olkin (KMO) value was 0.795, and Bartlett's value was 580.692, and the p-value was found to be statistically significant ($p < 0.00$).

The Relationship between Sociodemographic Characteristics and Scale Scores

A statistically significant difference was found between the satisfaction subscale scores between the mothers and fathers ($z = -1.994$, $p = 0.046$). A statistically significant difference was found between the level of difficulty experienced by the parents and the personal feelings subscale score and the total score ($p = 0.038$ and $p = 0.007$, respectively).

When the satisfaction subscale was divided into two groups as participants with low and high satisfaction scores scoring below and above the mean value, a statistically significant relationship was found between the participants with low and high scores and the current diagnosis of the child ($X^2 = 6.107$, $p = 0.013$). Parents of children diagnosed with ASD consisted of the participants with higher scores. There was no significant difference between the family's income level, the region of residence, the age of the child, the education level of the parents, the chronic disease of the parents and the subscale and total scores of the scale ($p > 0.05$).

DISCUSSION

This study reports the Turkish validity of the "Parental Satisfaction with Caregiving for Children with Developmental Disabilities" scale, which is used to evaluate the satisfaction of the parents of the child with special needs. Additionally, this study offers a different perspective on current knowledge on caregiving satisfaction: Personal satisfaction with caregiving for a child with developmental disabilities and satisfaction with having a child with developmental disabilities.

In the study in which the original of the scale was developed, the Cronbach alpha value of the satisfaction subscale was 0.889, while the Cronbach alpha value of the personal feelings subscale was 0.837 (15). In parallel with this, the Cronbach alpha values of the scale and the total reliability coefficient of the test were found to be quite high in this study. Comparison of Scale Scores among Participants Classified According to Different Characteristics were shown in Table 2. As can be seen, it is understood that there is a high degree of consistency in each item.

Developmental problems often cause children to need lifelong or chronic care. Families who cared for these children reported that they were more dissatisfied with their caring roles, their duties regarding childcare, and the feelings they experienced during caregiving (23). Parents

of children diagnosed with Autism Spectrum Disorder had significantly lower levels of satisfaction. It was thought that this might be due to the individuals diagnosed with Autism Spectrum Disorder in need of more support. The fact that these children have difficulties in expressing their needs due to their communication problems and the accompanying of many psychopathologies to the OSB, especially Intellectual Disability and behavioral problems, may increase the need for support (24).

Table 2. Comparison of Scale Scores Among Participants Classified According to Different Characteristics

	Scale Points		
	Satisfaction	Personal Feelings	Total
Parent			
Mother	9 ± 2.8	10.1 ± 4.1	19.1 ± 6.1
Father	10.4 ± 4.3	10.6 ± 3.9	21.1 ± 7
Difficulty Expressed in the Process			
No Difficulty	9.3 ± 3.1	9.5 ± 2.9	18.9 ± 5.5
Difficulty	9.2 ± 3.2	10.2 ± 4.1	19.4 ± 5.8
There is a lot of difficulty	11.1 ± 4.8	12.1 ± 4.9	23.2 ± 8.5

Behavioral problems present in ASD can be challenging for the caregiving that parents should perform (25). Singh et al. (2007) reported that parental training to reduce the behavioral problems of children with developmental difficulties increased satisfaction with parenting skills (26). Therefore, focusing on behavioral problems in such children's early intervention programs can both improve the child's behavioral difficulties and positively affect parental satisfaction.

In our study, it was observed that the satisfaction level of the parents was not affected by the gender factor of the children. This situation suggests the fact that "child's behavior" rather than "gender" is more effective on parental satisfaction. While there was data in the literature (27) that caring for a girl with special needs puts more pressure on families and the level of satisfaction is lower, no such difference was found in our study.

Mothers had higher levels of satisfaction than fathers. In the literature, it is stated that mothers take more responsibilities and experience more stress during the care process, but fathers take more responsibility for out-of-home support. In this context, fathers work harder to obtain more financial resources (28). Considering the low financial income of the majority of the participants, it was thought that fathers might seek more financial support in this process. This situation may have increased the stress level on fathers and caused their satisfaction levels to be lower.

In this study, there was no difference in terms of socio-demographic characteristics of families who care for children with special needs, such as income level, the region of residence, age of the child they have, parental education level, and chronic disease of the parents. This

may be related to the influence of the current religious beliefs of the province in which we conducted the study. It is known that religious beliefs can affect parents' perceptions of dealing with a child's disability in different cultures.

The relationship between the care and upbringing of a child with special needs and parental satisfaction is a complex and operational process. Therefore, the level of satisfaction with caregiving may be related to the degree of satisfaction the caregiver provides with their dedication or physical and emotional efforts.

This degree of satisfaction is also unlikely to increase immediately but may increase with time and effort. The significant relationship between the level of difficulty expressed by the parents in the process and the scale scores provides additional evidence for the validity of the scale.

LIMITATIONS

This study has some limitations and the results should be evaluated in this context. Participants were only parents of children with special needs who applied to a university health facility, so our sample may not be representative of the general population. In addition, the fact that the equivalent scale and the test repetition method used in the original development of the scale were not used within the scope of the evaluation of validity and reliability are among the other limitations of the study.

CONCLUSION

Consequently, clinicians can use this scale as part of an assessment strategy for children with special needs and their parents.

This scale can be used to identify parents with special needs children who may need additional support and to understand the impact of interventions on these parents. In addition, this scale can help countries improve their service approach to health policy practitioners and professionals and raise awareness of the needs of these parents. Therefore, the scale can be used by clinicians to identify parents at risk of low caregiver satisfaction. In addition, the scale can be used to monitor changes as a result of the interventions provided to the child and family, taking into account the satisfaction of parents of service providers such as parent education courses, counseling, or therapy programs.

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