



Evaluation of Marriage Integration and Psychological Resilience of Parents with Children with Down Syndrome and Cerebral Palsy

Down Sendromlu ve Serebral Palsili Çocuğu Olan Ebeveynlerin Evlilik Uyumu ve Psikolojik Dayanıklılıklarının Değerlendirilmesi

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Abstract

Aim: This study was conducted to evaluate marital adjustment and psychological resilience of parents with children with Down Syndrome and Cerebral Palsy who are individuals with disabilities.

Material and Method: This descriptive study was conducted with the parents of children with Down syndrome and cerebral palsy who are being educated in Bingöl Special Education and Rehabilitation Center. Personal information form, Psychological Resilience Scale for Adults and Marital Adjustment Scale were used between February and May. The data were analyzed by transferring to SPSS 26 package program in computer environment. Chi-square, T test, Mann Whitney U and Kruskal-Wallis H were used. Pearson correlation analysis was used to analyze the relationships. $P<.05$ was preferred for statistical significance.

Results: A statistically significant ($p<.001$) positive correlation was found between the mean scores of Psychological Resilience Scale for Adults and Marital Adjustment of parents with Down Syndrome and Cerebral Palsy. As a result of the independent samples t-test, it was found that there was no statistically significant difference between the two groups ($p>.05$). As a result of the Kruskal Wallis H test between the educational level of the parents with a child with Down Syndrome, it was found that there was a statistically significant difference between the groups ($p<.05$).

Conclusion: It has been determined that demographic characteristics do not affect the marital adjustment and psychological resilience of parents of children with down syndrome and cerebral palsy. Marital adjustment and psychological resilience are compatible.

Keywords: Down syndrome, cerebral palsy, marital adjustment, pediatric nursing, psychological resilience

Öz

Amaç: Bu çalışma engelli bireyler olan Down sendromlu ve Serebral Palsili çocuğu olan ebeveynlerin evlilik uyumunu ve psikolojik dayanıklılığını değerlendirmek amacıyla yapılmıştır.

Gereç ve Yöntem: Tanımlayıcı tipte olan bu çalışma Bingöl özel eğitim ve rehabilitasyon merkezinde eğitim görmekte olan Down sendromlu ve Serebral palsili çocukların ebeveynleri ile yürütülmüştür. Araştırma Şubat-Mayıs tarihleri arasında; kişisel bilgi formu, Yetişkinler İçin Psikolojik Dayanıklılık Ölçeği, Evlilik Uyumu Ölçeği kullanılarak elde edilmiştir. Veriler bilgisayar ortamında SPSS 26 paket programına aktararak analiz edilmiştir. Ki Kare, T testi, Mann Whitney U ve Kruskal-Wallis H kullanılmıştır. İlişkilerin incelenmesinde Pearson korelasyon analizi kullanılmıştır. İstatistiksel anlamlılık için $p<.05$ tercih edilmiştir.

Bulgular: Down sendromu ve Serebral çocuğa sahip ebeveynlerin Evlilik Uyumu Ölçeği ve Yetişkinler İçin Psikolojik Dayanıklılık Ölçeği puan ortalamaları arasında pozitif yönde korelasyon istatistiksel açıdan anlamlı ($p<.001$) bulunmuştur. Down sendromu ve Serebral çocuğa sahip ebeveynlerin Evlilik Uyumu Ölçeği ve Yetişkinler İçin Psikolojik Dayanıklılık Ölçeği puan ortalaması yapılan bağımsız örneklem t testi sonucunda iki grup arasında istatistiksel açıdan anlamlı bir farklılık olmadığı ($p>.05$) bulunmuştur. DS hastası çocuğa sahip ebeveynler içerisinde eğitim düzeyi arasında yapılan Kruskal Wallis H testi sonucunda gruplar arasında istatistiksel açıdan anlamlı bir farklılık olduğu ($p<.05$) bulunmuştur.

Sonuç: Down sendromlu ve Serebral palsili çocuğu olan ebeveynlerin evlilik uyumu ve psikolojik dayanıklılıklarını demografik özelliklerin etkilemediği belirlenmiştir Evlilik uyumu ile psikolojik dayanıklılık ise uyumludur.

Anahtar Kelimeler: Down sendromu, serebral palsy, evlilik uyumu, pediatri hemşireliği, psikolojik dayanıklılık



INTRODUCTION

Disability, which is expressed as the inability of the individual to fulfill the roles that he/she should fulfill due to age, gender, socio-cultural differences and which arises for different reasons, is examined under five main headings: orthopedic, hearing, vision, mental and speech.^[1] It is known that 15% of the world population, i.e. more than 1000 million people, has a disability. According to this information, 1 out of 7 people is disabled. It has been found that more than 93 million of this population consists of children under the age of 15. In our country, it is estimated that there are more than 5.5-6 million disabled children.^[2]

There are some disability groups in the world that define the concept of developmental disability. Down Syndrome (DS) is one of these disability groups. DS is a disease of genetic origin, seen in nations in different geographies and occurs due to the excess number of chromosomes in the cell.^[3] Although the birth rate of babies with DS varies according to the sources, it is generally defined as 1 in 600 live births or 1 in 1000 live births. It has been reported that the number of individuals with DS in our country is around 70,000 in line with uncertain data.^[4] Another disability group is cerebral palsy (CP). Cerebral means related to the brain. Palsy means weakness or problem in muscle use. CP is an abnormality that results from abnormal brain development or damage to the developing brain and affects a person's ability to control their brain.^[5] Various population-based research reports worldwide estimate the prevalence of the disease to be approximately 1.5-4 per 1000 children.^[6] In Türkiye, it has been concluded that the prevalence of CP is 4.4 per 1000 live births.^[7]

One of the basic concepts addressed in marriage studies is marital adjustment.^[8] Marital adjustment is a concept related to the level of meeting the needs of couples in the marriage process and how satisfied they are with the marriage. In addition to being much more important at the beginning of marriage, it is a process that needs to be protected and maintained throughout life.^[9,10] While studies have focused on resilience in children and adolescents, the number of studies on resilience in adults and caregivers has increased recently. Psychological resilience is a characteristic or personal ability that enables individuals who can overcome the current difficulties despite the difficulties and develop more than expected to survive, the ability to adapt quickly in the face of stressful life experiences and the ability to overcome the traumas experienced.^[11]

Each parent wants a healthy child to be born for the continuation of his/her generation and directs his/her life within the framework of these expectations.^[12] However, when it is determined that the child has a disability, the discrepancy between the actual situation and expectations emerges.^[13] Regardless of the degree of disability, having a disabled child affects the family emotionally, socially, physically and economically and may cause problems in marital adjustment.^[14,15]

Parents of individuals with mental or physical disabilities often need psychological support. Nurses reduce the burden of the family with the interventions they plan to improve the well-being of children with disabilities. They partially meet the psychological support needed by the family and reduce the depression levels of parents.^[16] Pediatric nurses should be able to provide all kinds of support and interventions to children and their families who have problems within the framework of their roles of supporting child and family health, advocacy, education and counseling.^[17]

When the studies involving parents with children with disabilities are examined, it is seen that studies have been conducted on the difficulties experienced by parents, life satisfaction, psychological resilience, care burden, and marital adjustment. There are very few studies on the psychological well-being of families of children with Down syndrome and cerebral palsy. The aim of this study was to evaluate marital adjustment and psychological resilience of parents with children with DS and CP.

METHOD AND METHOD

Research Ethics and Institutional Consent

In order to conduct the research, approval was obtained from Dicle University Social and Human Sciences Ethics Committee on 22.12.2023. After the Ethics Committee approval was obtained, institutional permission was obtained from Bingöl Provincial Directorate of National Education (Number/Date: 97250045-21.02.2024) for the rehabilitation centers where the research would be conducted. Written and verbal permission was obtained from parents who met the criteria for inclusion in the research sample. The data were collected with the "Informed Consent Form", which included information about the purpose, duration, and implementation of the study, that participation in the study was voluntary, that the names of the participants would be kept confidential, and that they could leave the study at any time. Permission was obtained by e-mail from the authors who performed the validity and reliability of the scales to be used in the study.

Type of Research

In this study, a correlational model was used to test the marital adjustment and psychological resilience and sociodemographic characteristics of parents with children with DS and CP. This study is cross-sectional and correlational descriptive type.

Population and Sample of the Study

The population of the study consisted of the parents of students with DS and CP enrolled in the Private Dünyam Special Education and Rehabilitation Center and Private Mucize Special Education and Rehabilitation Center affiliated to Bingöl Directorate of National Education

between February 2024 and June 2024. The sample size was 140 parents of students. Of these parents, 70 were parents of children with DS and the other 70 were parents of children with CP.

Post hoc power analysis was performed to determine the adequate sample size and effect size for the study. Power analysis was performed with the G*Power 3.1.9.4 package program.^[18] For the calculation of the effect size, Marital Adjustment Scale (MAS) and Psychological Resilience Scale for Adults (PRSA) were taken as reference. According to the calculation based on the relevant references, the effect size (ρ) = .23, Power ($1 - \beta$) = .99 for the SP group, while the effect size (ρ) = .69, Power ($1 - \beta$) = 1.0 for the DS group. The obtained values show that the sample size of the study and the effect sizes of the variables are sufficient.

Data Collection Tools

Personal Information Form: It is a form developed by the researcher in order to determine the characteristics of the sample group clearly and explicitly. The form included questions including sociodemographic characteristics and personal information such as age, gender, occupation and educational status of the parents, number of children in the family, and whether they wanted another child after the disabled child.^[19,20] The personal information form is given in Appendix 10.1.

Marital Adjustment Scale (MAS): Developed by Locke and Wallace in 1959, the MAS was adapted into Turkish by Tutarel and Kışlak in 1999. The scale consists of 15 items. Each item receives a score between 0 and 6, which differs according to the number of options. Accordingly, item 1 is evaluated between 0-6 points, items 2-9 are evaluated between 0-5 points, items 10 and 14 are evaluated between 0-2 points, items 11 and 13 are evaluated between 0-3 points, item 12 is evaluated between 0 points if the option of staying at home for one of the spouses and doing something outside for the other is selected, 1 point if the option of doing something outside is selected for each of the spouses, 2 points if the option of staying at home is selected for each of the spouses, and item 15 is evaluated between 0-2 points. The total score obtained from the scale varies between 0-60. Scores above 43 points are considered harmonious in terms of marital relations, while scores below 43 points are considered incompatible. Scores go from incompatibility to compatibility. As a result of validity and reliability studies, the Cronbach alpha value of the scale was found to be .84.^[21] According to the findings obtained, Cronbach's α reliability coefficients were calculated as .95 in the group with CP and .90 in the group with DS.

Psychological Resilience Scale for Adults (PRSA): It was developed by Friborg et al. in 2003 and adapted into Turkish by Basım and Çetin (2011). The scale initially consisted of six sub-dimensions: structural style, future perception, self-perception, social competence, social resources, and family harmony. The increase in the total score to be obtained from

the scale consisting of a total of 33 items in 5-point Likert type indicates that the psychological resilience level of the individual is high. The internal consistency coefficients of the scale were calculated as .80 for 'Self Perception', .75 for 'Future Perception', .82 for 'Social Competence', .86 for 'Family Adjustment', .84 for 'Social Resources' and .76 for 'Structural Style'.^[22] According to the findings obtained, Cronbach α reliability coefficients were calculated as .92 in the group with CP and .94 in the group with DS.

Evaluation of Data

The data obtained in the study were analyzed using SPSS (Statistical Package for Social Sciences) 26.0 program. Skewness and Kurtosis values, which are descriptive statistical measures, were taken into consideration to determine whether the data showed normal distribution.^[23] If the Skewness and Kurtosis values are between +2.0 and -2.0, it can be said that the data are normally distributed.^[24] Accordingly, when the scales used in this study were analyzed in terms of skewness and kurtosis values, it was determined that the data showed normal distribution. In the evaluation of the data, numbers, averages and percentages were used for descriptive analysis. Chi-square analysis was used to compare the demographic characteristics of parents with CP and DS and t-test was used to evaluate the differences between the MAS and PRSA variables in parents with CP and DS. For variables that did not show normal distribution, Mann-Whitney U and Kruskal-Wallis H tests were used to evaluate the differences in the mean scores of the MAS and PRSA of parents with CP and DS children according to demographic characteristics. Pearson correlation analysis was used to examine the relationships. For statistical significance, $p < .05$ was preferred.

Data Collection

The data were collected between February 2024 and May 2024. The research sample consisted of 140 disabled parents. The Personal Information Form, MAS and PRSA, which were created to determine the demographic characteristics of the parents who made up the research sample, were collected by face-to-face interview method through the researcher to the parents of children with CP and DS receiving education in Bingöl Private World Special Education and Rehabilitation Center and Bingöl Private Mucize Special Education and Rehabilitation Center. Written and verbal consent was obtained from the parents who participated in the study. These scales were administered by the researcher using the face-to-face method, which took an average of 10-15 minutes.

RESULTS

Of the parents, 67.1% were housewives, 71.4% were women, 31.4% were primary school graduates, and 31.4% had three children. The rate of those who have no other disabled children is 95.7%. The rate of those who do not plan to have another child is 63.6% (**Table 1**).

Table 1. Socio-Demographic Characteristics of Parents of Children with Cerebral Palsy and Down Syndrome

Variable	Category	N	%
Occupation	Housewife	94	67.1
	Self-employed	33	23.6
	Civil Servant	13	9.3
Gender	Female	100	71.4
	Male	40	28.6
Level of education	Illiterate	24	17.1
	Primary School	44	31.4
	Secondary School	23	16.4
	High School	33	23.6
	Bachelor's degree and above	16	11.4
Number of children	One	20	14.3
	Two	38	27.1
	Three	44	31.4
	Four or more	38	27.1
Do you have other children with disabilities?	Yes	6	4.3
	No	134	95.7
Do you plan to have children again?	Yes	51	36.4
	No	89	63.6

N: number of samples; %: percentage

As a result of the chi-square test on occupational distribution among parents of children with CP and parents of children with DS, it was found that there was no statistically significant difference between the two groups (X^2 : 1.217; $p>.05$) (**Table 2**).

As a result of the chi-square test on the distribution between the genders of parents of children with CP and parents of children with DS, it was found that there was no statistically significant difference between the two groups (X^2 : .560; $p>.05$) (**Table 2**).

As a result of the chi-square test on the distribution of educational status between the parents of children with CP and parents of children with DS, it was found that there was no statistically significant difference between the two groups (X^2 : 9.216; $p>.05$) (**Table 2**).

As a result of the chi-square test on the distribution of the number of children between parents with CP and parents with DS, it was found that there was no statistically significant difference between the two groups (X^2 : 1.838; $p>.05$) (**Table 2**).

As a result of the chi-square test on the distribution of parents of children with CP and parents of children with DS having other disabled children, it was found that there was no statistically significant difference between the two groups (X^2 : .697; $p>.05$) (**Table 2**).

As a result of the chi-square test on the distribution of parents with a child with CP and parents with a child with DS considering having another child, it was found that there was no statistically significant difference between the two groups (X^2 : 3.732; $p>.05$) (**Table 2**).

Table 2. Comparison of Demographic Characteristics of Parents of Children with Cerebral Palsy and Down Syndrome

Variable	Category	Cerebral Palsy		Down Syndrome		Significance
		N	%	N	%	
Occupation	Housewife	50	71.4	44	62.9	X^2 : 1.217 p : .544
	Self-employed	14	20.0	19	27.1	
	Civil Servant	6	8.6	7	10.0	
Gender	Female	52	74.3	48	68.6	X^2 : .560 p : .454
	Male	18	25.7	22	31.4	
Level of education	Illiterate	8	11.4	16	22.9	X^2 : 9.216 p : .056
	Primary School	21	30.0	23	32.9	
	Secondary School	9	12.9	14	20.0	
	High School	23	32.9	10	14.3	
	Bachelor's degree and above	9	12.9	7	10.0	
Number of children	One	12	17.1	8	11.4	X^2 : 1.838 p : .607
	Two	19	27.1	19	27.1	
	Three	23	32.9	21	30.0	
	Four or more	16	22.9	22	31.4	
Do you have other children with disabilities?	Yes	4	5.7	2	2.9	X^2 : .697 p : .404
	No	66	94.3	68	97.1	
Do you plan to have children again?	Yes	31	44.3	20	28.6	X^2 : 3.732 p : .053
	No	39	55.7	50	71.4	

 X^2 : Chi-square analysis; N: sample size; %: percentage

The mean score of MAS was 38.70 ± 13.54 in the group with CP and 41.41 ± 11.05 in the group with DS, and as a result of the independent samples t test, it was found that there was no statistically significant difference between the two groups (t : -1.300; $p>.05$) (**Table 3**). According to this finding, the level of marital adjustment of parents of children with CP and DS did not differ. The mean score of the PRSA was 118.11 ± 24.93 in the group with CP and 119.94 ± 26.67 in the group with DS, and as a result of the independent samples t test, it was found that there was no statistically significant difference between the two groups (t : .419; $p>.05$) (**Table 3**). According to this finding, the level of psychological resilience of parents of children with CP and DS does not differ.

Table 3. Distribution of MAS and PRSA Variables of Parents of Children with Cerebral Palsy and Down Syndrome

Variable	Cerebral Palsy		Down Syndrome		Significance	
	\bar{x}	SS	\bar{x}	SS		
MAS	38.70	13.54	41.41	11.05	t : -1.300	p : .196
PRSA	118.11	24.93	119.94	26.67	t : -.419	p : .676

 \bar{x} : mean; SD: Standard deviation; MAS: Marital adjustment scale; PRSA: Psychological resilience scale for adults; t : Independent samples t test

The mean score of the MAS scale used in the study was 38.7 ± 13.5 in the group with CP and 41.4 ± 11.1 in the group with DS, and the mean score of the PRSA scale was 118.1 ± 24.9 in the group with CP and 119.9 ± 26.7 in the group with DS. A statistically significant ($r: .587$; $p < .001$) positive correlation was found between the mean scores of the MAS and PRSA of parents with children with CP (Table 4). According to this finding, as the level of marital adjustment increases in parents with a child with CP, the level of psychological resilience also increases.

A statistically significant ($r: .691$; $p < .001$) positive correlation was found between the mean scores of MAS and PRSA of parents with children with DS (Table 4). According to this finding, as the level of marital adjustment increases in parents with a child with DS, the level of psychological resilience also increases.

Table 4. Mean, Correlation, Normality and Reliability Findings of MAS and PRSA in Parents with Children with Cerebral Palsy and Down Syndrome

Group	Variable	\bar{x}	SS	r	Skw.	Krt.	α
Cerebral Palsy (n:70)	MAS	38.7	13.5	.587*	-1.032	.746	.95
	PRSA	118.1	24.9		-.383	.286	.92
Down Syndrome (n:70)	MAS	41.4	11.1	.691*	-.701	.031	.90
	PRSA	119.9	26.7		-.095	-.692	.94

* $p < .001$; \bar{x} : mean; SD: Standard deviation; r: Pearson correlation; Skw: Skewness; Krt: Kurtosis; MAS: Marital adjustment scale; PRSA: Psychological resilience scale for adults; α : Cronbach's α

DISCUSSION

In this study in which marital adjustment and psychological resilience of parents with children with DS and CP were evaluated, scale scores of parents of children with the disease were compared according to their sociodemographic characteristics. Through the data obtained from this study, it was examined whether the problems experienced by the parents in both disease groups differed according to the disease group. We think that this study comparing both disease groups will bring a different perspective to the academia.

It was determined that there was no significant difference in the answers given to the question of whether a child had been had or considered after a child with a disability in individuals with children in both disease groups. There is no literature study that exactly matches this study. However, in a previous study, it was found that 66.2% of disabled parents answered no and 33.8% answered yes to the question "Do you think of having another child after a disabled child and do you have another child?"^[25] Müller et al. found that having a child with CP decreased the birth rate regardless of birth order and severity level.^[26] In our study, it was found that 63.6% answered no to this question (Table 1). However, no significant difference was found between whether a child was considered after the disabled child (Table 2).

There are similar studies comparing different types of disabilities in terms of marital adjustment and psychological resilience. In our study, no significant relationship was found between marital adjustment and psychological resilience of parents with children with DS and CP in terms of demographic characteristics (Table 3). For example, Friedman found that parents with children with autism and intellectual disabilities did not experience a significant difference in terms of marital adjustment. This shows that parents have similar attitudes towards different disabilities of the child.^[27,28] In addition, mothers with children with normal development, autism and DS were compared in terms of marital satisfaction and it was determined that mothers with children with autism had lower marital satisfaction scores.^[29]

Pinar found that the psychological resilience of parents of children with borderline intellectual disabilities was lower than parents with moderate and mild intellectual disabilities and parents with children with DS.^[30] Another study examined the relationship between parenting stress levels of mothers of children with different levels and characteristics of special needs and various psychological characteristics of mothers. Najimi et al. stated that psychological characteristics of the mother such as marital satisfaction, psychological problems and coping styles are important determinants of parenting stress.^[31] Ören and Aydin examined the psychological characteristics of parents with mentally or physically disabled children.

According to the results obtained by Küçük Alemdar, parents of children with physical disabilities had higher life satisfaction than parents of children with intellectual disability.^[32] Soliman et al. stated that families with children with CP face many difficulties and problems. They determined that affecting the anxiety levels of mothers as one of them.^[33] It was determined that unhealthy family functioning was parallel to depressive disorders of parents. It is stated that unhealthy family organization points to unhealthy individuals and healthy family organization points to healthy individuals.^[34] In contrast to these studies, there are studies indicating that the presence of a disabled child in the family has no effect on marital order.^[35] The data we obtained in our study indicate that marital adjustment scores and psychological resilience scores of parents with children with DS and CP are directly proportional (Table 4). According to this result, marital adjustment and psychological resilience should be evaluated together and considered as a common denominator in solving problems.

CONCLUSIONS

This study evaluated marital adjustment and psychological resilience of parents with children with DS and CP. The results of the evaluation are as follows.

- In this study, the demographic characteristics of parents with children with CP and DS were similar.

- The level of marital adjustment and psychological resilience of parents with children with CP and DS did not vary according to demographic characteristics.
- The level of marital adjustment and psychological resilience of parents with children with CP do not vary according to occupation, educational status, number of children, and whether or not they plan to have children again. The level of marital adjustment of male parents with a child with CP is higher than that of female parents. On the other hand, the level of psychological resilience in parents with children with CP does not vary according to gender.
- Marital adjustment level and psychological resilience level of parents with children with DS do not vary according to occupation, gender, number of children, and whether or not they plan to have children again. However, it was found that education level made a significant difference in marital adjustment of parents with children with DS.
- As the level of marital adjustment increases in parents with children with CP and DS, the level of psychological resilience also increases.

Those that can be added to make the study more qualified:

- The spouses of married individuals should also be included in the study.

ETHICAL DECLARATIONS

Ethics Committee Approval: The study was carried out with the permission of Dicle University Social and Human Sciences Ethics Committee (Date: 22.12.2023, Decision No: 299).

Informed Consent: Because the study was designed retrospectively, no written informed consent form was obtained from patients.

Referee Evaluation Process: Externally peer-reviewed.

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