



Original Article

Determination of the self-efficacy levels of parents with a child with cerebral palsy and the comparison of the parental self-efficacy levels

Merve Aşkın Ceran,¹ Burcu Ceylan²

¹Dialysis Program, Kto Karatay University, Vocational School of Health Services, Konya

²Department of Mental Health Psychiatric Nursing, Necmettin Erbakan University Faculty of Nursing, Konya

Abstract

Objectives: This study was conducted to determine the self-efficacy levels of the parents of children with cerebral palsy (CP) and compare their parental self-efficacy levels.

Methods: The sample of this descriptive study consisted of 153 parents (106 mothers and 47 fathers) with children with CP who were attending four different special education and rehabilitation centers affiliated to Konya Provincial Directorate of National Education. Of these parents, 47 were married couples. The data were collected using the Information Form and the Parenting Self-Efficacy Instrument for Children with Disabilities (PSICD) between February and March 2019.

Results: The average age of children with CP was 8.83 ± 4.58 and 54.2% of them were male, 72.5% of them did not attend school, 43.8% of them were congenitally handicapped and 46.4% of them had more than two affected extremities. The average self-efficacy perception score of the parents was found to be 5.91 ± 1.03 . It was determined that the parents whose family type is nuclear family and whose children are girls have higher self-efficacy scores. The average self-efficacy score of the parents according to the affected limb was found to be significant. Parental self-efficacy score was found to be lower in parents with children with more than two affected limbs than parents with one or two affected limbs. The analyses performed to reveal the effects of the disease on the lives of the individuals showed that there is a difference between the self-efficacy mean scores of the parents and out-of-home responsibilities and the time allocated to others. It was also found that there was a difference between the emotional states of anger and sadness experienced by the individuals and the self-efficacy mean scores of the parents. A significant difference was found between the male parents' sense of affection and the parents' self-efficacy mean scores. It was determined that the feeling of affection was higher.

Conclusion: The mean self-efficacy score of the parents with a child with CP was found to be high, which is affected by some characteristics of the parents. The self-efficacy mean scores of the parents were similar.

Keywords: Cerebral palsy; parent; self-efficacy.

One of the most common causes of disability in childhood is Cerebral palsy (CP) that develops due to a damage to the central nervous system (CNS).^[1,2] Today, despite the advancement of technology, early diagnosis and family orientation, there is no significant decrease in the incidence of CP. In fact, there is even an increase in CP incidences due to the increase in premature life expectancy.^[2,3] It is reported that the preva-

lence of CP is 2–3 per 1000 live births in the world^[4] and between 1.7–2.0 in developing countries.^[5] In Turkey, this ratio is between 1.1–4.4 per thousand births.^[3,6] Children with CP have deficiencies in some developmental areas; other important systems that work well in their bodies are ignored; and there is social prejudice that due to their inability to perform self-care on their own, they are increasingly more dependent on their

Address for correspondence: Merve Aşkın Ceran, KTO Karatay Üniversitesi Sağlık Hizmetleri Meslek Yüksekokulu, Konya, Turkey

Phone: 444 12 51 / 754 **E-mail:** ms.cerancer3642@gmail.com **ORCID:** 0000-0002-2296-2572

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What is presently known on this subject?

- Having a child with CP, caring for him, and leading life with him may create physical, social and psychological burdens in the lives of parents and may negatively affect their self-efficacy level. Low self-efficacy levels particularly in mothers who provide primary care negatively affects both the mother and the child, and causes various psychological problems. Fathers, who are affected by this situation almost as much as the mother, are not adequately addressed in the literature.

What does this article add to the existing knowledge?

- Our study emphasizes that having a child with CP equally affects the self-efficacy levels of the mother and father. Researchers are recommended to conduct studies that evaluate parents together.

What are the implications for practice?

- The results of this study provide an insight into the importance of evaluating the self-efficacy of parents with children with CP and having supportive interventional practices.

families, and as a result, parents may experience physical, psychological, emotional, social and economic problems.^[2,7-9]

Having an individual with a disability in the family may cause family members to assume many different roles besides family roles.^[10] Having a child with CP, caring for him, and maintaining life with him can have many negative effects on the lives of the parents and can create additional burden on the parents.^[11] Parents may have to choose between their own needs, the needs of other members of the family and the needs of the child with CP and spend substantial amount of their time with their disabled child.^[12]

While some parents can easily cope with negativities and additional burdens, some may find it difficult to adapt to the condition of their children,^[13] which can negatively affect the caregiver's care burden, stress level, physical activity level, quality of life, psychological status and self-efficacy perception.^[14-16] Self-efficacy refers to people's beliefs in their ability to control the events that develop in their lives and it directly affects human behavior.^[17,18] Individuals' positive emotions and strength in the face of negative events increase their success and personal satisfaction, and strengthens their self-efficacy level.^[17,19] In the literature, parental self-efficacy has been defined as the ability of parents with children with developmental disabilities to cope with the difficulties in their lives and reach their planned goals for the future.^[20] It is stated that parents with high levels of self-efficacy are psychologically healthy individuals who can easily cope with distressing situations and who have a positive point of view.^[21] In addition, many studies have revealed that parents with strong self-efficacy beliefs in situations such as improving the condition of the disabled child, reducing the level of addiction, and supporting the caregiving parent exhibit positive parental behaviors.^[22-24] Some studies indicate that a high level of parental self-efficacy plays an important role in controlling and coping with factors that cause stress, anxiety, depression, despair, pessimism, hopelessness and negative thoughts in families with disabled children such as CP.^[18,23,25] Providing continuous education is an important part of care for these children who need daily care and for their families.^[26,27] It is necessary to determine the self-efficacy levels of parents in order for nurses to plan interventions to

improve parents' self-efficacy, to raise awareness and to provide support. This study aimed to determine the self-efficacy levels of the parents with children with CP and to compare the parental self-efficacy levels.

Research Questions

Our study addresses the following research questions:

- What are the self-efficacy levels of parents who have a child with CP?
- Is there a difference between parental self-efficacy mean scores according to the characteristics of the parents?
- Is there a difference between parental self-efficacy mean scores according to the characteristics of the child?
- Is there a difference between parental self-efficacy mean scores according to the effects on parents' lives?
- Is there a difference between the self-efficacy levels of parents?

Materials and Method**Research Type and Place**

This descriptive study was carried out in four special education and rehabilitation centers affiliated to Konya Provincial Directorate of National Education between February and March 2019.

Research Population and the Sample

The target population of the study was the parents of the children with CP who were attending the four centers from which institutional permission was obtained (n=570). With the recommendation of the institutions, single parents and parents in fragmented families were not included in the study. The findings of the study by Cavkaytar et al.^[28] (2014) were used to determine the participants, and the standard deviation score (Sd=6.5) of the Parenting Self-Efficacy Instrument for Children with Disabilities (PSICD) was taken into account. The $n = N \times \frac{Z^2 \times d^2}{(N-1) \times d^2}$ formula, which is used when the target population is known, was applied in the calculation. In the Formula, the confidence level was accepted as 95% and deviation was accepted as d=1.^[29] As a result, the number of participants was determined as 153 parents. Of these participants, 47 are married couples (n=94).

Dependent Variable

The Parenting Self-Efficacy Instrument for Children with Disabilities (PSICD) Score

Independent Variables

- Characteristics of the parents
- Characteristics of the child
- The effects on parents' lives
- Parents' feelings about having a child with CP

Data Collection Tools and Procedure

The researchers visited four rehabilitation centers from which institutional permission was obtained, informed the parents about the research, and obtained consent from the parents who agreed to participate in the study. Since it was difficult to reach the fathers, the questionnaire was given to the mothers and the fathers were asked to fill it in at home. The mothers brought the completed questionnaires back the following day. The data collection tools were piloted before the study and no intervention was made by the researchers during the process of filling out tools. The Information Form includes 15 questions which evaluate parental characteristics (age, gender, marital status, number of children, educational status, working status, perception of economic status, presence of a physical or mental health problem that requires regular medication), child characteristics (age, gender, age at which the child became disabled, school status and the number of affected extremities), the effects of CP on life, and the feelings of parents about having a child with CP. The Parenting Self-Efficacy Instrument for Children with Disabilities (PSICD) was developed by Guimond, Moore, Aier, Maxon, and Diken (2005), adapted into Turkish by Diken^[30] (2007), and revised by Cavkaytar et al.^[28] (2014). It is used to measure the self-efficacy perceptions of parents of children with disabilities regarding parenting skills.^[29] The scale is a 7-point Likert type scale and consists of 17 items in total. The lowest score that can be obtained from the scale is 17 points, while the highest score is 119 points. The Cronbach's Alpha internal consistency coefficient of the scale is 0.95. In this study, the Cronbach's Alpha internal consistency coefficient was calculated as 0.96.

Data Analysis

The data were analyzed using the SPSS (Statistical Package for Social Sciences) for Windows 23.0 program. The socio-demographic characteristics of mothers and fathers were analyzed using numbers, percentages, and the arithmetic mean for the age variable. The descriptive statistics (minimum, maximum, mean and standard deviation) was calculated according to the scores obtained by the parents from the scales used in the study. The compliance of the data to normal distribution was examined using the Shapiro-Wilk test. In order to compare parents' self-efficacy mean scores and their socio-demographic characteristics, independent samples t-test was used in measurements with a normal distribution, and the Mann Whitney U test was used for measurements that did not have a normal distribution. Since normal distribution was not appropriate, the Kruskal-Wallis test was used to compare the sociodemographic characteristics with a categorical variable that includes more than two groups and parents' self-efficacy mean scores. In case of a difference, the Bonferroni analysis was performed as a post hoc analysis to determine the group from which the difference originated. Mann Whitney U test was used to compare the feelings of the parents about having a child with CP and the self-efficacy mean scores of the parents, since the data did not have normal distribution.

Research Ethics

Written permission was obtained from KTO Karatay University, Faculty of Medicine, Non-Pharmaceuticals and Non-Medical Device Research Ethics Committee (28.02.2019, Decision No: 1087), the institutions, the authors for the use of the scale, and the parents.

Results

The average age of the parents who participated in the study was 37.35 ± 7.00 years, 69.3% of them were women and all of them were married. 27.5% of the individuals were primary school graduates, 71.9% had a nuclear family structure, 66.0% were housewives, 67.3% did not work and 76.5% had a perception of moderate economic status. 54.2% of the children with CP were male; 85.6% did not use drugs, 72.5% did not go to school, and 46.4% had more than two affected extremities. The mean self-efficacy score of the parents was found to be 5.91 ± 1.03 .

A difference was observed between the mean self-efficacy scores of the parents according to the family type, child's gender and the affected extremity ($p < 0.05$). Parents with a nuclear family type ($p < 0.001$) and a female child ($p = 0.024$) were found to have higher self-efficacy scores. The mean self-efficacy score of the parents according to the affected extremity was found to be significant ($p = 0.016$). In order to evaluate from which group the difference originated, the Bonferroni test was applied, and it was found that the parental self-efficacy scores of parents with children with more than two affected extremities were lower than those of the parents with children with one or two affected extremities (Table 1).

The results of the correlation analysis of parents' mean perception scores of how much their lives have been affected by the disease and their mean PSICD scores are given in Table 2. No statistically significant difference was found between the parents' perceptions of the effect of the disease on their lives and the mean PSICD score ($p > 0.05$).

Table 3 presents the findings pertaining to the comparison of the mean self-efficacy scores of the parents according to their feelings about having a child with CP. No statistically significant difference was found between the feelings of unhappiness, anxiety, and anger and the mean PSICD score ($p > 0.05$). On the other hand, a statistically significant difference was found between the feelings of compassion, sadness, concerns about the future and the mean PSICD score ($p < 0.05$).

Discussion

In this study, the mean self-efficacy score of the parents was found to be 5.91 ± 1.03 , meaning that their self-efficacy levels were high. High self-efficacy is an important factor in parents' exhibiting appropriate behavior towards their children with developmental delay.^[18] Similarly, when parental self-efficacy is high, it is believed that parents deal with challenging

Table 1. Comparison of parents' socio-demographic characteristics and parents' self-efficacy scores (n=153)

Socio-demographic variables	Min/Max n (%)	Mean±SD Q2 (Q1-Q3)	Test value/SD	p
Age	21/58	37.35±7.00	r=-0.096	=0.239
Gender				
Female	106 (69.3)	5.94±1.01	t=0.537	=0.592
Male	47 (30.7)	5.85±1.09		
Family type				
Nuclear family	110 (71.9)	6.10±1.01	t=3.623	<0.001*
Extended family	43 (28.1)	5.45±0.96		
Occupation				
Worker/civil servant	23 (15)	105 (94-114)	KW=2.79	=0.425
Tradesman/freelance	28 (18.3)	100 (83-110)		
Retired	1 (0.7)	102 (102-102)		
Housewife	101 (66)	106 (95-114)		
Economic status				
Good	31 (20.3)	107 (94-113)	KW=4.673	=0.097
Moderate	11 (76.5)	104 (94-114)		
Poor	5 (3.2)	90 (74-100)		
Child gender				
Female	83 (54.2)	5.74±1.13	t=-2.278	=0.024*
Male	70 (45.8)	6.12±0.86		
School attendance				
Yes	42 (27.5)	6.10±0.76	t=1.337	=0.183
No	111 (72.5)	5.85±1.11		
Affected extremity				
One extremity	27 (17.6)	108 (100-118)	KW=24.113	=0.000*
Two extremities	55 (35.9)	109 (102-117)		
More than two extremities	71 (46.4)	97 (83-107)		

and stressful situations effectively and give more appropriate feedback to their children.^[31] The studies that evaluated the self-efficacy levels of parents with children who were diagnosed with a disability or whose development was at risk reported that the level of parental self-efficacy was high^[32-35] or medium.^[36] The reason why parental self-efficacy levels of parents were high in this study is that parents receive support from the institutions, regular supportive training sessions are held to meet the needs of the parents, and parents can easily and quickly access all kinds of information regarding their children's needs via the internet. In addition, the fatalistic perspective of the parents may have led to high level parental self-efficacy.

It was found that there was no relationship between the parental self-efficacy level and the parents' age, gender, educational status, working status, perception of economic status and health status that would require regular medication use (Table 1). There are studies in the literature that have reached similar results.^[33,34,37-41] However, Aksoy and Diken^[19] (2009) stated in their study that parental self-efficacy level is affected by variables such as socio-economic status and maternal

age. Our study revealed that parents' self-efficacy scores were higher in nuclear families, which may be attributed to the fact that the majority of the families who participated in the study have a nuclear family structure (71.9%), the number of dependents is low, and the parents support each other when caring for a child with developmental disabilities.

In the study, a difference was found between the self-efficacy mean scores of the parents according to the family type ($p<0.05$). It was determined that the parents whose family type is nuclear family had higher self-efficacy scores. Unlike our research findings, a study conducted by Beral^[36] (2010) on autistic children revealed that there was no significant difference between the parental self-efficacy score and family type. Our study further revealed a relationship between the gender of the child and the average self-efficacy score of the parents. As opposed to the findings of our study, Çattık^[43] (2015) reported that the age and gender of the child did not lead to a significant difference in parental self-efficacy scores.^[42] Furthermore, a difference was found between the mean parental self-efficacy scores according to the affected extremity. One of the most important findings of this study is that the paren-

Table 2. Comparison of parents' self-efficacy mean scores according to the effect of having a child with CP on their lives (n=153)

Characteristics	n	%	Test value	K-W	p
Mean rank					
Your relationship with others					
Affected	19	12.4	90.68	5.482	0.065
Not affected	96	62.7	79.50		
Highly affected	38	24.8	63.84		
Mean±SD					
Self-care				F	p
Affected	35	22.9	5.61±0.99	2.151	0.120
Slightly affected	71	46.4	6.05±1.04		
Highly affected	47	30.7	5.94±1.02		
Mean±SD					
Responsibilities				F	p
Affected	40	26.1	5.97±1.05	0.083	0.920
Slightly affected	78	51.0	5.90±0.99		
Highly affected	35	22.9	5.89±1.12		
Mean rank					
Out-of-home responsibilities				K-W	p
Affected	62	40.5	87.61	6.108	0.047*
Slightly affected	74	48.4	69.02		
Highly affected	17	11.1	73.03		
Mean rank					
Child care				K-W	p
Affected	26	17.0	90.17	3.895	0.143
Slightly affected	83	54.2	71.28		
Highly affected	44	28.8	80.01		
Mean±SD					
Time allocated to others				F	p
Affected	46	30.1	6.02±1.06	3.105	0.048*
Slightly affected	77	50.3	6.01±0.85		
Highly affected	30	19.6	5.50±1.03		

tal self-efficacy level decreases as the number of extremities affected by the disease increases (Table 1). It is estimated that the level of parental self-efficacy may be low due to the decrease in parents' expectation from the child as CP is a lifelong disease and due to the learned helplessness experienced over time.

Results pertaining to the correlation between the effect of the disease on parents' lives and the mean PSICD score were also given. No statistically significant difference was found between the parents' perceptions of the state of being affected by the disease of their children and the mean PSICD score ($p>0.05$) (Table 2). Different from our findings, some studies revealed that mothers with disabled children behave more cautiously and limit themselves in their social relationships, do not spare enough time for themselves and their environment, have to leave their jobs to provide better care for their children, and their roles and responsibilities in the family are affected.^[15,43-47] Kayhan and Piştav-Akmeşe^[44] (2016) examined

the perceived social support levels of mothers with children with CP and found that the level of perceived social support differs based on the frequency of face-to-face meetings with relatives, neighbors or friends, the frequency of going out for work, and the amount of care burden assumed.^[43]

One important finding of our study is that half of the parents who have children with CP do not feel compassion, and those with high compassion have a high level of parental self-efficacy (Table 3). Compassion is defined in the dictionary as "affection, pity and feeling of love" (Turkish Language Association). Compassion, which involves love, mercy and help, has three important dimensions. The first of these is the cognitive dimension, which is the ability to fully understand someone else's situation. The second dimension is the emotional dimension which refers to feeling what another person feels, and the final dimension is the behavioral dimension that stimulates us to respond in the most useful way.^[47-50] Half of the parents with disabled children do not feel compassion, which

Table 3. Comparison of parents' feelings about having a child with CP and parents' mean self-efficacy scores (n=153)

Characteristics	n	%	Test value Mean±SD	t	p
Unhappiness					
Yes	44	28.8	5.77±1.21	-1.124	0.263
No	109	71.2	5.97±0.95		
Anger					
Yes	23	15.0	5.49±1.20	-2.164	0,051
No	130	85.5	5.99±0.98		
Anxiety					
Yes	71	46.4	5.92±0.95	0.037	0.799
No	82	53.6	5.91±1.10		
Compassion					
Yes	75	49.0	6.02±1.12	1.209	0.016*
No	78	51.0	5.82±0.93		
Sadness					
Yes	102	66.7	5.78±1.13	-2.190	0.048*
No	51	33.3	6.17±0.74		
Concerns about the future					
Yes	98	64.1	5.83±1.00	-1.338	0.040*
No	55	35.9	6.06±1.07		

can be considered as a defense mechanism or as an avoidance behavior through emotional insulation not to feel the pain that the child experiences. Parents cognitively know that the disease is incurable and there is no way to reach the desired goal. Furthermore, the meaning they assign to life and expectations from life are lost; they experience difficulties in problem solving.^[44,51] In addition, the high level of parental self-efficacy in those with a sense of compassion can be considered as an important power in supporting the child with CP and in individual coping. The analyses revealed a difference between the parents' mean self-efficacy scores according to the state of sadness and concerns about the future ($p < 0.05$). It was found that those who said they do not feel sad ($p = 0.048$) and concerned about the future ($p = 0.040$) had higher parental self-efficacy mean score. Studies arguing that families experience sadness the most support our research findings.^[52,53] Despite the institutional support and high parental self-efficacy levels, the level of sadness is high because parents think of the future, what parents will face in the future is uncertain, and they do not know how the child will continue his/her life when they get older or die. The anxiety they feel about future and sadness are interrelated. Previous studies also maintain that families are primarily concerned about who will provide care for their child in the future.^[8,51,54-57]

Our study further revealed that the parental self-efficacy levels of couple parents are similar and high (Table 4). Although it is seen in the literature that mothers generally assume the care burden, it has been stated in some studies that fathers, grandmothers and grandparents contribute to child care.^[51,58]

Parents' experiencing similar problems together may cause the parental self-efficacy level to be similar. Overbeek et al.^[55] (2016) reported that parents who have a visually and mentally disabled child have higher parental self-efficacy scores than parents who have only a visually impaired child. Özkul^[59] (2015) investigated the parental self-efficacy perceptions of the fathers of 48–60-month-old children and found that the fathers who are together with the mothers have higher self-efficacy scores. Karlıoğlu and Yıldırım Sarı^[56] (2019) conducted a study the fathers of mentally retarded children and they found that the parental self-efficacy level of fathers was high. It was observed that when fathers talk to the child, play with and take care of him/her, and help the mother, the development of the child is positively affected and the mother can spare time for herself.^[20,58] It is stated that the father, who supports the mother and child emotionally, has an important role in the development of intra-family relations.^[58] It is also maintained that successful parenting experiences and success stories related to individuals with similar characteristics affect the family positively and feed self-efficacy beliefs.^[23]

Conclusion

The self-efficacy levels of the parents with children with CP were found to be high. The parents in nuclear families were found to have higher self-efficacy levels than those in extended families. Parents' self-efficacy level gets significantly lower as the number of affected extremities increases. This may be attributed to the fact that the care burden of the parents increases in parallel to the increase in the level of dependence

of the disabled child. Although half of the parents who have a child with CP do not feel compassion, the level of parental self-efficacy was found to be high in those with high compassion. The majority of the parents experience sadness and feel anxious about the future, and the parental self-efficacy scores of the parents experiencing these feelings are lower than those who do not experience these feelings. Based on our findings, it can be recommended to prepare educational programs for these families so that they can cope with their psychological and educational problems, to perform some interventional practices to support the self-efficacy of parents with children with CP, to conduct studies that evaluate mothers and fathers with children with CP together, to carry out qualitative studies including families, and to increase the awareness of health-care professionals about the importance of self-efficacy level of parents who have children with CP.

Limitations

The limitations of the study are as follows:

- The research was conducted only in centers in Konya city center that gave institutional permission.
- The study was performed with children with a single type of disability, which is CP.
- Single parent and fragmented family parents were not allowed to participate in the study,
- It was not possible to reach all the fathers in the sample.

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