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Factors Affecting the Caregiver Difficulties in Caring of Children With Cerebral Palsy

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ABSTRACT

Background and Objectives: Cerebral Palsy (CP) can trouble caregivers in the families of children with cerebral palsy. This study aimed to investigate the factors affecting caregiver troubles of the families of children with CP.

Methods: In this cross-sectional study, 121 children with CP and their parents participated. Factors such as gross motor function, manual ability, communication function, eating and drinking abilities, seizure, IQ, age, gender, auditory and visual problems were evaluated in children, and their predictive power to the caregiver difficulties was measured.

Results: The Mean±SD of age of the children in the study was 9.7±4.6 years. The linear regression results showed that none of the evaluated factors were predictors of caregiver difficulties.

Conclusion: The present study showed that none of the factors mentioned could predict caregivers' troubles. Future studies on the factors affecting the caregiver difficulty should be conducted to provide additional information or to draw more complex models to describe caregivers' difficulties in parents of children with CP in Iran.

Keywords: Cerebral palsy, Caregivers, Difficulties

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What is "already known" in this topic:

Cerebral palsy is one of the disorders that impose great difficulty on children and their families. Many factors affect caregiver difficulty.

What this article adds:

None of the mentioned personal factors could predict Caregiver difficulty.

Introduction

Disability not only affects children with disabilities but also impacts their families [1]. The biggest impact of this disability is on these parents is coping with different needs and characteristics of their children [2]. Parents of children with Cerebral Palsy (CP) have a key role in meeting the needs of these children, pursuing treatment, and providing various care for their special needs [3]. The stress and difficulties which affect these parents play a key role in their performance and the way that they manage the child. Cerebral palsy is one of the disorders that impose great difficulty on children and their families [4, 5].

CP is a complex disorder of varying degrees of motor and cognitive impairments. CP is a non-progressive neurological injury that results from brain damage before birth, during birth, or early childhood [6]. Although the impairment is static, the cascade of motor and functional impairments continue throughout the person's life [2].

Although motor dysfunction is a major symptom of cerebral palsy, many children with CP have significant problems in their cognitive, sensory, communication, and social skills [7]. These limitations require care and support for these children, far greater than normal children. This condition can result in significant difficulties for the families of these children [8]. The caregiver's inconvenience reflects the potential negative impact of a patient's illness on caregivers and includes multiple psychological, physical, emotional, social, and financial problems and difficulties of patient care. This concept has a complex and multifaceted conceptual structure and usually occurs when the patient needs more care and resources [9, 10]. According to the literature, caregiver difficulties can lead to mental and physical problems over the years [11]. Marrón et al. showed that the most important predictors of caregiver burden were the degree of disability, depression, and self-efficacy [12]. Sometimes family members of the patient who has a chronic illness are burdened with the patient's needs and problems. This is especially true for patients such as children with CP who are being cared at home [12].

Parents of children with CP are reported to have a high percentage of stress and caregiver problems [13]. These parents have higher levels of depression and anxiety, and typically experience lower life satisfaction, quality of life, and self-efficacy than parents of typically-developed children [14, 15]. Parkes et al. in a study on families and children with cerebral palsy in European countries, showed that parents of these children had a high degree of stress [16]. Pousada et al. found that caregiving burdens had a negative effect on the quality of life of caregivers and increased their stress too. They also mentioned that each society should demonstrate the factors affecting caregivers' burden to have the proper planning for this problem [17].

However, few studies have been conducted on the personal factors affecting the difficulties and burden of caregivers of children with CP in Iran [18]. The management of these caregiver difficulties has a significant impact on the child and the parents' function. Parents of children with CP are involved in daily care, child support, and coordination of services [3]. They play an important role in the rehabilitation of children with long-term disabilities and their health is of paramount importance [19]. The main question of this study is which factors affect the difficulties of caregivers of children with CP. Therefore, the present study was conducted to evaluate the personal factors affecting the difficulties of mothers of children with cerebral palsy in Iran.

Materials and Methods

Study design

The present study was a cross-sectional study conducted in Tehran City, Iran, in 2019.

Study participants

A multistage sampling method was used in this study to collect the study samples. At first, Tehran was divided into five parts: North, south, east, center, and west. In each of the five centers, a boys' school and a girls' school were selected for sampling. A number of students were randomly selected for sampling. Subsequently, research and informed consent forms were sent to the families of the children. Parents returned these forms after filling them out.

The inclusion criteria for the child were as follows: the child should be between 2 and 18 years old and be diagnosed with CP, according to a neurologist report. The parental inclusion criteria were as follows: parents should be able to read and write in Persian and were interested in participating in the study. Parents who did not complete the consent form or the study tools were excluded from the research process.

Outcome measures

Caregiver Difficulties Scale (CDS)

The Caregiver Difficulties Scale (CDS) was used to assess the caregivers of children with CP. The tool consists of 25 items, divided into 4 subtests of concern for the child (8 items), impact on self (7 items), support for caregiving (5 items), and social and economic strain (5 items) [18, 20]. Each item receives a score of 1 to 4. Higher scores indicate higher caregiver's difficulties. This tool has sufficient validity and reliability among Iranian mothers of children with CP [21].

The Gross Motor Function Classification System (GMFCS)

In this study, the Gross Motor Function Classification System (GMFCS) was used to classify the gross motor ability of children. GMFCS is based on active movement and emphasizes on gross motor movements. This classification system consists of 5 levels. In this system, differences are characterized by the ability to move long distances, the existence of functional limitations, the need for manual aids such as walkers, crutches, and canes or wheeled vehicles such as wheelchairs [22]. This scale is a valid and reliable tool for assessing gross motor function in children with CP. The reliability of the instrument is 0.93 [23].

The Manual Ability Classification System (MACS)

The Manual Ability Classification System (MACS) is a human hand motion classification system that describes how children aged 4 to 18 years with CP use their hands in daily activities. This tool focuses on using both hands together. The classification system uses five levels to categorize the functional levels of the hand. Level one is an indicator of minimal hand dysfunction. At this level, the child only has problems with tasks that require speed and accuracy. Level 5 represents the most impaired, the inability to manipulate objects, and limited ability to perform the simplest tasks [24]. This tool has good validity and reliability. The intra-cluster kappa coefficient of this questionnaire is 0.75 [25].

Communication Function Classification System (CFCS)

The Communication Function Classification System (CFCS) was used to assess the level of communication ability of children with cerebral palsy. This classification system is based on the effectiveness of the communication between the sender and receiver of information. This system classifies all communication modes, including speech, gesture, facial expression, and alternative communication methods. The reliability of the questionnaire is 0.74 [26].

Eating and Drinking Ability Classification System (EDACS)

The Eating And Drinking Ability Classification System (EDACS) system is used to measure a child's ability to eat and drink. This classification system includes the safety (aspiration and choking) of eating and drinking, the efficiency (food waste and speed of eating), and the amount of assistance a person needs while eating. It has good validity and reliability in children with CP. The Intraclass Correlation Coefficient (ICC) for this questionnaire is 0.86 and the kappa coefficient is 0.45 [27].

Cognitive level assessment

SPARCLE stands for the PARticipation Study of Children with CP Living in Europe. SPARKEL scale was used to assess participants' cognitive ability. This form is taken from the Sparkle project. The Sparkle scale categorizes children's cognitive ability according to the International Classification of Diseases, 10th revision (ICD10). Children who score below 50 on this scale have severe cognitive impairment. A score of 50-70 indicates mild cognitive impairment, and such children may suffer from learning disabilities [28].

Demographic questionnaire

A demographic questionnaire was used to collect demographic data, including child age, type of cerebral palsy, gender, use of assistive devices, visual and hearing problems, parent's age, the gender of parents, type of residence, level of education, and parents' occupation.

Study procedure

In this study, one occupational therapist was responsible for data collection and necessary communications. After obtaining the necessary permits, this person (second author) went to schools and collect information on children who were eligible to participate in the study. After collecting the demographic information and performing the cognitive test, all other forms, including the informed consent form, GMFCS, EDACS, CFCS, and CDS questionnaires were sent for parents. when the parents returned the forms, the therapist also evaluated the GMFCS, EDACS, and CFCS for assurance.

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Data analysis

To evaluate the data and investigate the relationships between them, SPSS V. 24 sofwaer was used. The linear regression statistical test was used to investigate the predictive power of different variables (personal factors) on the dependent variable (caregivers' difficulties).

Results

Demographic variables of caregiver difficulties are shown in Table 1.

Table 2 presents the Mean±SD of the quantitative variables and their relationship with caregiver difficulties. The results of the regression modeling which is presented in the following tables show that none of these factors are good predictors of parental difficulties for children with CP. Of 121 children participating in the study, 76 (62.8%) were male and 45 (37.2%) were female. The Mean±SD of the age of the children in the study was 9.7±4.6 years. Table 3 presents information on demographic variables.

Discussion

The study aimed to investigate the factors affecting caregiver difficulties of parents with CP children. The results showed that none of the factors could be a good predictor of caregiver difficulty in the families of children with CP. At first glance, it seems surprising that none of these 12 factors could predict the caregiver difficulty of families of children with CP, but it should be noted that caregiver difficulty is a complex and multi-faceted issue and sometimes in various diseases had no significant relationship with disease severity [29]. Besides, all 12 factors examined were related to the child, not the child's caregivers. In research designed for the

Table 1. Demographic variables of caregiver difficulties

Variables		No.	Mean±SD
			Caregiver Difficulties
Child's gender	Male	75	66.6±9.5
	Female	45	61.7±12.2
Mother's education level	Illiterate	3	60.3±12.9
	Elementary or secondary	26	66±11.3
	Diploma	56	66±10.8
	Bachelor or Master's degree	35	65.4±12.2
Father's education level	Illiterate	2	51±7.8
	Elementary and secondary	29	67.5±9.8
	Diploma	48	65.7±11.5
	Bachelor and Master's degree	40	65.1±11.6
Mother's job	Housewife	100	65.9±10.8
	Employed or self-employed	19	65.2±14.2
Father's job	Employed	41	62.9±11.9
	Self-employed	71	66.7±10.6
	Jobless	6	60.1±10.7
Region	North	27	64±10.8
	South	54	67.7±10.9
	East	5	63.2±5.1
	West	8	68.6±12.2
	Center	25	64.7±13
Rehab services	Yes	93	64.8±10.6
	No	27	70.4±13

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Variables		No.	Mean±SD
			Caregiver Difficulties
Cerebral palsy type	Spastic hemiplegia	42	67.8±11.7
	Spastic diplegia	13	61.5±10.4
	Spastic quadriplegia	38	64.5±10.8
	Athetoid	11	67.3±12.1
	Ataxic	6	65.6±9.7
	Dystonic	7	64.2±10.6
Visual impairment	Poor vision	24	65.7±11.1
	No problem	94	65.9±11.5
Auditory impairment	Yes	2	67.5±7.8
	No problem	117	35.8±11.4
Seizure	Yes	31	64.3±10.2
	No	89	66.4±11.6
Walking ability	Yes	53	67.3±11.7
	No	67	64.7±10.9
IQ level	> 70	36	67.9±13
	50–70	39	64.9±11.4
	< 50	44	65±9.7
The manual ability classification system	1	26	67.3±14.4
	2	23	68±11.8
	3	19	64±11.3
	4	26	64.5±9
	5	25	65.2±10.1
The gross motor function classification system	1	12	67±13.2
	2	35	67.7±11.5
	3	14	69.5±12.5
	4	24	63.2±9.7
	5	34	63.9±10.9
The communication function classification system	1	41	68.4±12.8
	2	20	65.5±10
	3	21	64.2±12
	4	10	61.3±6.4
	5	27	65.3±10.4
The eating and drinking ability classification system	1	57	67±12.4
	2	32	65.1±9.4
	3	17	63.2±9.7
	4	10	62.9±10.7
	5	3	75.6±18.6

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Table 2. The Mean±SD of quantitative variables and their relationship with caregivers' difficulties

Variables	No.	Mean±SD	Correlation	
			R	Sig.
Child's age	121	9.7±4.6	0.1	0.25
Father's age	116	42.7±6.9	0.06	0.46
Mother's age	121	38.2±6.2	0.09	0.3

validity and reliability of the burden-related questionnaires, caregiver-related factors are usually more correlated with caregiver difficulty than the patient-related factors [20, 30].

In a study by Whittingham et al. on the burden of care for the families of children with CP, child behavior, parental coping, and experiential avoidance were the best predictors of caregiving, of which 2 are related to parental characteristics [31].

In a study on several children with CP and their parents, Champa et al. found that parental contextual factors such as low income, rural residence, and male sex were mostly associated with parental care [18].

In 2000, Hwa and colleagues conducted a study on Korean families and their children. The results showed that the degree of children's handicap, familial relationship with the children, caregiver's health status, age of the children, and duration of treatment had the highest correlation with the caregiver difficulty [32].

Boztepe's study of the caregiver difficulty in families of children with CP who has leukemia showed that the presence of depression in the mother and the severity of the

Table 3. Stepwise linear regression for predicting caregiver difficulties

Variables	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% Confidence Interval for B	
	Model B	Std. Error	Beta			Lower Bound	Upper Bound
Constant	53.636	9.620	-	5.576	0.000	34.568	72.704
Age	0.115	0.293	0.038	0.392	0.696	-0.466	0.696
Caregiver	2.471	4.757	0.047	0.519	0.605	-6.959	11.901
visual	0.468	2.941	0.015	0.159	0.874	-5.361	6.298
Auditory problem	2.827	8.095	0.032	0.349	0.728	-13.219	18.873
Seizure	1.366	2.969	0.043	0.460	0.646	-4.519	7.251
Walking	-6.301	3.505	-0.226	-1.798	0.075	-13.248	0.647
CP type	-0.319	0.876	-0.034	-0.364	0.716	-2.055	1.417
IQ	0.007	1.681	0.000	0.004	0.997	-3.326	3.340
GMFCS	-1.821	1.289	-0.182	-1.413	0.161	-4.376	0.734
MACS	0.665	1.077	0.070	0.618	0.538	-1.469	2.800
CFCS	2.290	1.018	0.262	2.249	0.027	0.272	4.308
EDACS	1.020	1.494	0.082	0.683	0.496	-1.942	3.982

CP: Cerebral Palsy; GMFCS: Gross Motor Function Classification System; MACS: Manual Ability Classification System; CFCS: Communication Function Classification System; EDACS: Eating and Drinking Ability Classification System;

illness had the highest relationship with the caregiver difficulty [33].

Marrón et al. conducted a study in 2013 to evaluate the factors affecting parental care burden on children with CP in Spain. In this study, they used a regression model to analyze the obtained data. In their study, the degree of disability, parental depression, and self-efficacy had the highest association with caregiver difficulty in children with CP [34].

As observed in the above studies, caregiver-related factors were more related to the intensity of caregiver difficulty. Most of the mentioned studies have attempted to measure the correlation between child care and parent-child factors. It should be noted that, unlike correlation, which measures correlative factors, regression tries to establish causal and predictive relationships. Two or more variables can be correlated, but not necessarily predict each other [35]. In our study, none of the factors mentioned as independent variables (GMFCS, MACS, EDACS, CFCS, seizure, IQ, age, gender, and auditory and visual problem) cannot predict caregiver difficulty but it may correlate with these factors.

It should be noted that the attitudes of families and individuals about disabilities are very influential on caregiver difficulty. If parents have negative attitudes about disabilities, they may experience more psychological stress, too. In Iranian culture, a family of a CP child at level 2 in GMFCS may feel significant pressure to raise their child, but on the other hand, a family of a CP child at level 5 in GMFCS may accept this issue and do not get into a serious mental pressure. Despite investigating various factors in children with CP, the main limitation of this study was not using factors measuring caregiver-related issues. Future studies could also address these areas. Besides, the results will be more reliable if future studies use a larger sample size.

Conclusion

Caregiver difficulty is a multifaceted and complex issue that can be influenced by various factors. Our study showed that none of the factors mentioned could predict caregiver difficulty. Future studies on factors affecting the caregiver difficulty should be conducted to provide additional information or to draw more complex models to describe caregiver difficulty in parents of children with cerebral palsy.

Ethical Considerations

Compliance with ethical guidelines

This study was approved by the Ethics Committee of Iran University of Medical Sciences (IR.IUMS.REC.1397.1170). The participants signed an informed consent form after being informed of the privacy policy as well as the purpose, importance, methods, and risks associated with this study.

Authors' contributions

Project design and supervise, final approval of the version to be published, and interpreting and discussing Results: Alireza Jamali and Malek Amini; Data collection: Maryam Karimpour and Ata Farajzadeh; Statistical analysis: Seyed Hassan Sanei.

Conflict of interest

The authors declared no conflict of interest.

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شناسایی فاکتورهای موثر بر مشکلات مراقبین کودکان فلج مغزی

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چکیده

مقدمه فلج مغزی می‌تواند باعث مشکلات مراقبتی برای خانواده‌های کودکان مبتلا به فلج مغزی باشد. مطالعه حاضر با هدف بررسی عوامل مؤثر بر مشکلات مراقبتی خانواده‌های دارای کودکان فلج مغزی انجام شد.

مواد و روش‌ها در این مطالعه که از نوع بررسی مقطعی بود، ۱۲۱ کودک مبتلا به فلج مغزی و والدین آنها مشارکت کردند و عواملی نظیر عملکرد حرکتی درشت، توانایی دستی و عملکرد ارتباطی، توانایی خوردن و آشامیدنی، تشنج، ضریب هوشی، سن، جنسیت، مشکلات شنوایی و بینایی در کودکان مورد بررسی قرار گرفت و رابطه پیش‌بینی کننده آنها با مشکلات مراقب محاسبه شد.

یافته‌ها میانگین و انحراف سن کودکان مورد مطالعه (۹/۷±۴/۶) بود. نتایج رگرسیون خطی نشان داد که هیچ یک از عوامل ارزیابی شده پیش‌بینی کننده مشکلات مراقبتی کودکان فلج مغزی در ایران نیستند.

نتیجه گیری مطالعه حاضر نشان داد که هیچ یک از عوامل ذکر شده نمی تواند مشکلات مراقبین را پیش‌بینی کند. برای ارائه اطلاعات اضافی یا ترسیم مدل‌های پیچیده‌تر برای توصیف مشکل مراقبت در والدین کودکان مبتلا به فلج مغزی در ایران، مطالعات آینده در مورد عوامل مؤثر بر مشکل مراقب با حجم نمونه بالاتر باید انجام شود.

کلیدواژه‌ها:

فلج مغزی، مراقبین، مشکلات

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