



A CROSS-SECTIONAL STUDY TO EVALUATE THE QUALITY OF LIFE OF CAREGIVERS FOR CHILDREN WITH CEREBRAL PALSY

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ABSTRACT

Cerebral Palsy (CP) includes a group of disorders specified by long-term disabilities that influence the Quality of Life (QoL) of either patients or their caregivers. The purpose of the present research was to evaluate the QoL of caregivers of CP patients. A cross-sectional study was conducted for one year (June 2017 to July 2018) to evaluate the QoL of caregivers of 4–18 years old cerebral palsy children using a self-structured questionnaire. Logistic regression was utilized in the analysis. A total of 93 caregivers of CP children participated in the study.

In most cases, parents were the caregivers (94.7%), of which mothers were the main care providers (71%). More than half (57.2%) of the caregivers had a low QoL with a mean of 8.98 ± 3.22 . Physical health, social health, family and social support, and financial problems showed a significant relationship with the overall quality score of the caregivers of cerebral palsy patients ($p < 0.05$). The Quality of Life of parents of children with CP was influenced in all areas. The average overall QoL scores were considerably lower for caregivers of a child with CP, and mothers were the main care providers in the family. A multidisciplinary team should be involved to provide maximal benefit for the child suffering from CP and improve the health and Quality of Life of caregivers of children with cerebral palsy.

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Introduction

Cerebral Palsy (CP) is defined as a non-progressive insult to an infant's developing brain that may occur before, during, or after birth [1]. It is considered as the foremost prevalent motor disability in childhood [2-4]. Its incidence ranges from 1.5–2.5 per 1000 live births, and this range increases to 40–100 per 1000 live births in premature births or extremely low birth weights infants [5]. In 2014, the incidence rate of CP in Saudi Arabia was 2.5 per 1000 live births, with more than 200,000 new cases each year. With such an incidence rate, it is considered an enormous burden for both families and the health system in Saudi Arabia [6].

Early in childhood, patients with CP suffer from different forms of functional limitations, all of which make them need more effort and special care compared to other children of the same age and gender [1, 7]. As parents and caregivers have a crucial effect on improving the Quality of Life for CP patients, it's essential to ensure their well-being as reflected on their children [8]. Dealing with the physical, emotional, and financial stress of having a child with lifelong disabilities can be exhausting.

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Moreover, the stigma of the developmentally delayed child and the parents' sadness and worries about the future can unfavorably influence the caregivers' Quality of Life [9, 10].

World Health Organization defined quality of Life (QoL) as "an individual's perception of their position in life in the context of the value systems and culture where they live and concerning their purposes, standards, concerns, and expectations. It can be a broad-ranging concept influenced in a complicated way by the person's physical well-being, mental state, individual opinions, social connections and their correlation to notable specifications of their environment" [11].

Accordingly, it is crucial to study the effect of having a child with CP on QoL for caregivers as only a few numbers of published papers were directed toward this problem in Saudi Arabia [12, 13]. Hence, this research was carried out to evaluate the attitude, knowledge, and practice of caregivers of children with cerebral palsy and highlight the effect of cerebral palsy and disability on the caregivers.

Materials and Methods

A cross-sectional research was carried out in King Abdul-Aziz University Hospital (KAUH) in Jeddah for one year (June 2017 to July 2018) to evaluate the Quality of Life of caregivers of cerebral palsy children. The Institutional ethical committee confirmed the study protocol. Verbal informed consent was taken from the mothers of participants after negotiating the purpose of the study.

Study Population and Eligibility Criteria

All those caring the children with CP aged 4 to 18 years attending KAUH during the study period were included in the study. Caregivers of CP children aged less than 4 years and more than 18 years were excluded.

Sample Size

A total of 129 mothers of children with CP were interviewed; 93 completed the questionnaire and the other 36 were deceased.

Data Collection

Data were collected by interviewing patients' mothers, or caregivers face to face at the pediatric outpatient clinic by the primary investigator. A self-structured printed questionnaire was distributed to mothers hand by hand to collect data about the sociodemographic and health characteristics of children: their age, gender, marital status, education, and occupation. Caregivers' relationship with their children was assessed by asking their relation with their child, hours of care, duration of care, the number of other children in their family, presence of another child with CP, and insurance status. Association of different domain scores to the caregiver QoL was assessed across physical, social, support, and financial domains.

Data Entry and Analysis

The Statistical Package of Social Sciences (SPSS) version 20 (IBM Corp. Released 2011. IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp.) was used to analyze the data. Descriptive statistics including standard deviation [SD], mean, percentages, and frequencies) were calculated for sociodemographics, overall and domain-specific QoL, and other parameters. A series of binary logistic regression models were structured to test the effect of the proposed factors on caregivers' QoL. To evaluate the goodness of fit of the models a Hosmer-Lemeshow Test (HLT) was utilized.

Results and Discussion

Totally 129 caregivers of children with CP were interviewed, of which 93 completed the questionnaire, and the other 36 were deceased. Sociodemographic specifications of caregivers are indicated in **Table 1**. Seventy-two (77.4%) of those who completed the questionnaire were females. About half of them (54.8%) were of age 31-40 years. Most of them were married (91.4%), housewives (69.9%), and at a secondary level of education (38.7%).

Table 1. Distribution of Sociodemographic Characteristics of Caregivers (n=93)

		N	%
Gender	Female	72	77.4
	Male	21	22.6
Age	16-30	15	16.1
	31-40	51	54.8
	41-49	19	20.4
	50-70	8	8.6
Marital status	Widow	1	1.1
	Single	3	3.2

	Divorced	4	4.3
	Married	85	91.4
Education	Not educated	7	7.5
	Primary	13	14.0
	Secondary	36	38.7
	Diploma	10	10.8
	University	27	29.1
Occupation	Unemployed	65	69.9
	Employed	28	30.1

In most cases, parents were the caregivers (94.7%), of which mothers were the main care providers (71%). Most caregivers had other children (78.6%), and (14.0%) had another child with CP. Nearly half of (51.6%) caregivers spent more than 18 hours in their child care, as shown in **Table 2**.

Table 2. Caregiver's relation to their Children

		N	%
Relation with the child	Mother	66	71.0
	Father	22	23.7
	Aunt	2	2.2
	Sister	1	1.1
	Brother	1	1.1
	Baby sitter	1	1.1
Hours of care	<6	13	14.0
	6 - 12	17	18.3
	12- 18	15	16.1
	>18	48	51.6
Duration of care (years)	4-8	39	41.9
	9-12	34	36.6
	13-18	20	21.5
Number of children in the family	None	3	3.2
	1-2	17	18.3
	3-4	46	49.5
	5-6	14	15.1
	>7	13	14.0
Another child with CP	No	80	86.0
	Yes	13	14.0
Insurance	No	69	74.2
	Yes	24	25.8

Regarding the initial findings of the present research, the QoL of caregivers is indicated in **Table 3**. The Caregiver's QoL ranged from 3-16 with a mean of 8.98 ± 3.22 . Moreover, more than half (57.2%) had a low Quality of Life. **Table 4** demonstrates the association of various domains, including physical and social health, family and social support, and financial problems, to the overall quality score of the caregivers. Each domain showed a significant relationship to the observed decrease in the QoL of caregivers ($p < 0.05$).

Table 3. Caregiver's QoL

Caregiver QoL	Minimum- Maximum	Median	IQR	High	Low
	3.0-16.0	8.98	6.0-11.0	40 (42.8%)	53 (57.2%)

IQR: Interquartile range

Table 4. Association of Different Domain Scores to the Caregiver Quality of Life

		Caregiver Quality of Life				P-value
		High		Low		
		N	%	N	%	
Physical score	0.00	1	2.2	9	18.8	<.001*
	1.00	19	42.2	36	75.0	
	2.00	4	8.9	2	4.2	
	3.00	21	46.7	1	2.1	
Social score	0.00	0	0.0	4	8.3	<.001*
	1.00	2	4.4	12	25.0	
	2.00	8	17.8	24	50.0	
	3.00	17	37.8	7	14.6	
	4.00	16	35.6	1	2.1	
	5.00	2	4.4	0	0.0	
Support score	.00	0	0.0	2	4.2	.001*
	1.00	0	0.0	5	10.4	
	2.00	2	4.4	9	18.8	
	3.00	13	28.9	19	39.6	
	4.00	19	42.2	10	20.8	
	5.00	11	24.4	3	6.3	
Financial score	.00	4	8.9	26	54.2	<.001*
	1.00	8	17.8	15	31.3	
	2.00	9	20.0	7	14.6	
	3.00	6	13.3	0	0.0	
	4.00	18	40.0	0	0.0	

*significant at $p < 0.05$.

On a rough assessment of caregivers' knowledge about CP, only 37.6% answered all questions correctly and were classified as having good knowledge. The rest of them were classified as having medium or poor knowledge. When asked about the cause of this condition, birth asphyxia was the most common given answer (39.8%). Surprisingly, 19.4% of caregivers didn't know the name of the condition of their child. However, almost all participants (97.7%) want to know more and are willing to learn.

Regarding physical health, 84.9% of participating caregivers were medically free. However, almost half of them (49.5%) reported daily tiredness, and taking care of their CP child was the leading cause in 48.4% of cases. To a different extent, 55.9% of caregivers had psychological and mental stresses due to taking care of their disabled child. Socially, a noticeable decrease in outdoor activities especially visiting family and friends, was reported by 58.1% of participants as they have to spend most of the day at the home to help their children. Fortunately, 29% had no problems at all in practicing their social activities as they used to do before having their child due to good family support. Marital problems were found in only twelve married couples participating in this survey. Of employed caregivers, more than half (55.6%) reported having problems at work due to their child's illness; 43% of them borrowed money to provide the needed care for their child. The financial burden of special child needs was an issue in 73.1% of families participating in this survey. Fortunately, 53.8% of families were receiving regular help from different charitable and governmental organizations. However, only 25.8% had health insurance covering the needed services beyond government organizations for CP patients.

Cerebral palsy (CP) was firstly explained in 1862 by an orthopedic surgeon named William James Little [14]. Patients with CP and their caregivers have to face various obstacles in their lives such as financial constraints, low availability of health services, far-distanced schools, and non-availability of specialized institutes, which affect patients and their family members and disrupt their QoL. Once the disability of their children is diagnosed, the caregivers have to go through various phases such as phases of confusion, despair, anger, denial, frustration, and finally, acceptance. The normal part of being a parent or caregiving is to take care of their child. Still, CP children need special care, which could enhance the burden and stress on the caregiver [15] and negatively impact the QoL of primary caregivers, who are usually the mothers in most instances. Hence, this research was carried out using the perspectives of the caregivers of cerebral palsy children.

Parents of a disabled child are usually the main care providers. Usually, mothers were the main care providers in our cohort (71%), and various other studies conducted by Zuurmond *et al.* (90%) [16], Chalipat *et al.* (63.3%) [17], and Mohammed *et al.* [18]. Researches carried out by Mobarak *et al.* [19] and Hartley *et al.* [20] found that the burden of care falls typically on a female member of the family and that high extents of anxiety and stress exist for the main caregiver.

Knowledge regarding a disease means having basic information related to the title of the illness, its mechanism, causes, and management, which was lacking in the present study as 19.4% of caregivers didn't know the name of their child's condition. In our study, 49.5% reported daily tiredness, and among them, 48.4% reported taking care of their CP child as the leading cause of their exhaustion. Mohammed *et al.* [18] also found that many caregivers felt fatigued during and at the end of the day in their evaluation. Mothers or caregivers should have a sound knowledge about the disease, its symptoms, mode of diagnosis, and various management options other than medications, surgery, and physiotherapy, which will help understand the disease better and improve overall QoL. On assessment, most of the caregivers were classified as having medium or poor knowledge in our study. The same results were obtained by Zuurmond *et al.* [16]. The caregivers had insufficient knowledge regarding CP, and traditional opinions about etiology related to witchcraft were amazingly strong in this rural region of Bangladesh.

Parents of disabled children like CP deal with the physical, emotional, and financial stress of having a child with lifelong disabilities, which can be exhausting. This demanding responsibility has a negative or unfavorable impact on their physical and psychological health, which deteriorates their QoL. In the present study, more than half (57.2%) of the caregivers had a low Quality of Life which was in line with several researches carried out in the past [16, 18, 21-29]. A research done by Zuurmond *et al.* [16] found that caregivers of children with cerebral palsy in rural Bangladesh had a significantly poorer QoL than caregivers of children without disabilities.

Tuna *et al.* [24] investigated the QoL of 40 primary caregivers of children by comparing them with children without CP and found that the scores for vitality, general health status, emotional states, and functional capacity were significantly lower. The pain domain was higher in the primary caregivers of children with CP in comparison to the control group. Mohammed *et al.* study [18] reported that the overall mean score was low (8.85, SD: 3.270) concerning the QoL of caregivers, which was almost similar to the mean score of our study (8.98±3.22). A study done by Chalipat *et al.* [17] found contradictory findings to the above studies and observed that 70% of parents reported their overall QoL as neither poor nor good. More than half of the parents were satisfied with their health status. Elena *et al.* [30] showed that the Quality of Life of caregivers is not a significant predictor of burden.

Since the QoL of CP patients depends upon their caregivers, it is of utmost importance that caregivers ensure their well-being. In our study, physical health, social health, family and social support, and financial problems showed a significant relationship to the overall quality score of the caregivers. Zuurmond *et al.* study [16] found statistically significant lower QoL scores ($p < 0.0001$) for all 8 domains (social functioning, physical functioning, emotional, cognitive functioning, daily activities, worry, communication, and family relationships) among the caregiver of a child with a disability in comparison to normative families. In Chalipat *et al.* study [17], the mean score of the social domain of Quality of Life of caregivers was the lowest (9.33±1.49 SD), followed by the psychological domain (18.23±1.50 SD).

Previous studies [15, 21, 22, 31, 32] found that the caregivers of children with acute clinical impairments, particularly concerning motor function, are more likely to have greater physical and mental distress than other caregivers. Mohammed *et al.* study [18] found the occupation of the caregiver as the only factor that showed a significant association with caregivers QoL as most of the mothers in the present research were housewives, which could affect their socioeconomic status and QoL. CP is a disabling disease that is expected to reduce the QoL of CP caregivers and patients. QoL is a subjective way to assess a person's feelings toward the different aspects of his life. We have chosen caregivers of CP children in our study, as caregiving of CP children is often a life commitment job, and there are long-lasting requirements and demands of care from the patient's side. This issue exposes parents to various stress and curbs their social, cultural, and professional opportunities [33]. All of these harms the caregivers as well as the patient's life and decrease their QoL.

Some limitations are present in our study. First of all, we have used the cross-sectional survey of questionnaire type so that respondents can read differently for each question. Subsequently, the answer will be according to their interpretation of the question, and causality cannot be inferred from these studies. Secondly, we have not used a standard questionnaire to assess the QoL of caregivers. Leisure activities of caregivers were not taken into account, and lastly, this was a single institutional study, so the study's findings cannot be generalized to other centers. Hence, further prospective studies should be conducted on the same topic with more subjects to assess more information.

Conclusion

More than half (57.2%) of the caregivers had a low QoL with a mean of 8.98±3.22. Physical health, social health, family and society support and financial problems showed a significant relationship to the overall quality score of the caregivers of cerebral palsy patients and mothers were the main care providers in the family. Since CP children face various challenges in their day to day routine, it is necessary for parents and caregivers to be understanding and have the patience to meet these challenges successfully and assist children with CP reach their potential. A multidisciplinary team should provide maximal benefit for the child suffering from CP and improve the QoL and wellbeing of caregivers of children with CP. Community and governmental support to families of children with special needs should be emphasized.

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