

Burden of Caregivers for Children with Cerebral Palsy at Center Pediatric Teaching Hospital in Baghdad

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ABSTRACT

Cerebral palsy affects muscular, motion, and movement ability. Encephalopathy develops when a child's brain is injured prior to or during the first three to five years of life. Additionally, this type of brain injury can result in other health concerns such as vision, hearing, speech, and learning difficulties. The study aims to assess burden of with caregivers at center paediatric teaching hospital in Baghdad city. From 15 November 2018 to 20 May 2019, a descriptive design was used to examine the burden on carers of children with cerebral palsy at Baghdad's central paediatric teaching hospital. A non-probability (purposive) sample of (95) caregivers at a central paediatric teaching hospital. The items assessing nurses' knowledge were graded on a Likert scale on three levels: always, occasionally, and never, and were scored as 3, 2, and 1. The researcher concludes from the study's findings that caregivers' psychological, social, and financial burdens were greater in severity of sickness groups than in moderate or mild illness. The researcher suggests a manual or pamphlet on how to manage children with cerebral palsy should be developed and provided to caregivers.



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1. INTRODUCTION

Cerebral palsy is a common childhood neurological condition that causes permanent impairment. Long-term care delivery might significantly impact a caregiver's health. The best treatment technique for CP children require a family-centered approach. The study's goal is to see how teaching careers of children with CP affects their quality of life and burden [1]. The brain is cerebral. Paralysis means weakness or immobility. Cerebral palsy affects 2–3 out of every 1,000 children with motor deficits. Cerebral palsy causes persistent movement and posture issues [2]. Cerebral palsy patients can use assistive technology (the ability to move in a coordinated and purposeful manner). Injuries to the brain that occur before, during, or after birth cause cerebral palsy. This brain damage can affect vision, hearing, and speech. LD. Treatment, rehabilitation, special equipment, and in certain cases, surgery can help with cerebral palsy. Infantile cerebral palsy is a common congenital (born) pediatric disease. US youngsters are affected by this [2]. We all know how vital it is to keep a child healthy, yet many parents are unaware of serious developmental disorders like cerebral palsy. The incidence is the number of new instances diagnosed over time. For example, in the United States, between 8000 and 10,000 children are born with cerebral palsy each year [4]. Decades of research have given

the following frequently cited figures in America: Currently, 764,000 people have cerebral palsy, 500,000 of them under 18. You're CP (US studies have shown rates as low as 2.3 per 1,000 children to 3.6 per 1,000 children). Every year, 10,000 babies are born with CP. The condition affects 8000-10,000 children and babies each year. Cerebral palsy affects 1200-1500 preschoolers each year [4].

2. Methodology

Design of the Study: A descriptive design was conducted on caregivers for children with cerebral palsy from 15 November 2018 till 20 May 2019 in order to assess burden of with caregivers at center pediatric teaching hospital in Baghdad.

Setting of the Study: The study was conducted at Central Child Hospital the Sample of the study: A purposive (non-probability) sample of (95) caregivers who were attending in central pediatric teaching hospital at unit.

Study Instrument: The questionnaire was created after a thorough examination of the relevant literature and studies. A four-part questionnaire was utilized to collect data: the first part is related to demographic data, the second part is related to psychology burden, the third part is psychosocial burden of children with cerebral palsy and the fourth part is financial burden. The elements assessing nurses' knowledge were graded on a Likert scale on three levels: always, occasionally, and never, with scores of 3, 2, and 1, respectively. Low = less than (66.66), Pass = greater than (66.66-77.77), moderate = greater than (77.78-88.88), and high = greater than (88.89-100), and these were computed using the following formula: $(100 - 66.66) / 3$ equates to 11.11.

Method: An interview with the sample utilizing a developed questionnaire was conducted, including self-reporting for burden. Data were collected from Dec 23 2018 to Feb 2019 Validity of the instrument: To assess the questionnaire's validity, a team of experts reviewed its content for clarity and suitability to the current study's goals.

Statistical Data Analysis: (Frequency, Percentages, and Cumulative) Score Mean (MS): A mean score of 1.5-2.5 was regarded significant, 2.5 was considered highly significant, and 1.5 was judged non-significant. The owing: = (3x Always, 2x Occasionally, 1x Never) relative sufficiency (RS) adequacy (RS) Lower than (66.66) was low, higher than (76.77) was moderate, and higher than (100.0). Relative Sufficiency by: Inferential Statistical Procedure: This approach was performed through the determination of: Chi-square (X²): It was utilized to establish a statistically significant association between nurses' knowledge and their demographic variables at a P 0.05 level of significance.

3. Results

Table1. Distribution of the Demographic Variables for Sample (N = 95)

Variables	Frequency	Percent
Caregiver's age (Years): Mean (SD) = 32.3 ± 9.2		
18-28	35	36.8
29-38	38	40.0
39-48	17	17.9
≥ 49	5	5.3
Caregiver's gender		

male	39	41.1
female	56	58.9
Child's age (Years): Mean (SD) = 3.2 ± 1.93		
< One	11	11.6
1-2	25	26.3
3 - 4	34	35.8
≥ 5	25	26.3
Child's gender		
Male	54	56.8
Female	42	43.2
Severity of Illness		
Mild	17	17.9
Moderate	51	53.7
Severe	27	28.4
Caregiver's relationship with the child		
Father	29	30.5
Mother	45	47.4
Brother	2	2.1
Sister	3	3.2
Other	16	16.8
Caregiver's level of edu.		
Unable to write and read	3	3.1
Reads and writes	8	8.4
Elementary School Graduate	21	22.1
Middle School graduate	24	25.3
High school graduate	20	21.1
Institute/College graduate	17	17.9
Graduate degree	2	2.1
Caregiver's occupation		
Out of work (or Housewife)	48	50.5
Retired	3	3.2
Freelancer	27	28.4
Employee	17	17.9
Is there a blood relationship between the parents?		

Yes	55	57.9
No	40	42.1
Residency		
Urban	89	93.7
Rural	6	6.3

The caregiver's mean age was 32.3 9.2 years; two-fifths (n = 38; 40.0 percent) were between the ages of (29-38) years, followed by those between the ages of (18-28) years (n = 35; 36.8 percent), those between the ages of (39-48) years (n = 17; 17.9 percent), and those aged 49 years or older (n = 5; 5.3 percent). More than a half were females (n = 56; 58.9%) compared to males (n = 39; 41.1%). The mean child age was 3.2 1.93; more than a third (n = 34; 35.8 percent) were in the age group (3-4 years), followed by those in the age group (1-2) years and those aged five years or over (n = 25; 26.3 percent), and those younger than one-year-old (n = 11; 11.6 percent). Furthermore, more than a half were males (n = 54; 56.8%) compared to females (n = 42; 43.2 %).

The illness was moderate in severity for more than a half of children (n = 51; 53.7%), followed by severe illness (n = 27; 28.4%), and mild illness (n = 17; 17.9%). Less than a half of caregivers were mothers of ill children (n = 45; 47.4%), followed by fathers (n = 29; 30.5%), other persons (n = 16; 16.8%), sisters (n = 3; 3.2%), and brothers (n = 2; 2.1%). Concerning caregivers' educational attainment, around a quarter (n = 24; 25.3 percent) were middle school graduates, by those who were Primary School Graduates (n = 21; 22.1 percent), and those who were Secondary School Graduates (n = 21; 22.1 %). Those with an institute/college degree (n = 20; 21.1 percent), those who could read and write (N = 8; 8.4 percent), those who could not read and write (n = 3; 3.2 percent), and those with a university degree (n = 2; 2.1 percent)). Regarding caregivers' occupation, around a half were out of job (n = 48; 50.5%), followed by those who were freelancers (n = 27; 28.4%), those who were employees (n = 17; 17.9%), and those who were retired (n = 3; 3.2%). More than a half of parents reported that there is a blood relationship between them (n = 55; 57.9%). Ultimately, the clear majority of caregivers reported that they live in urban areas (n = 89; 93.7%) compared to those who live in rural areas (n = 6; 6.3%).

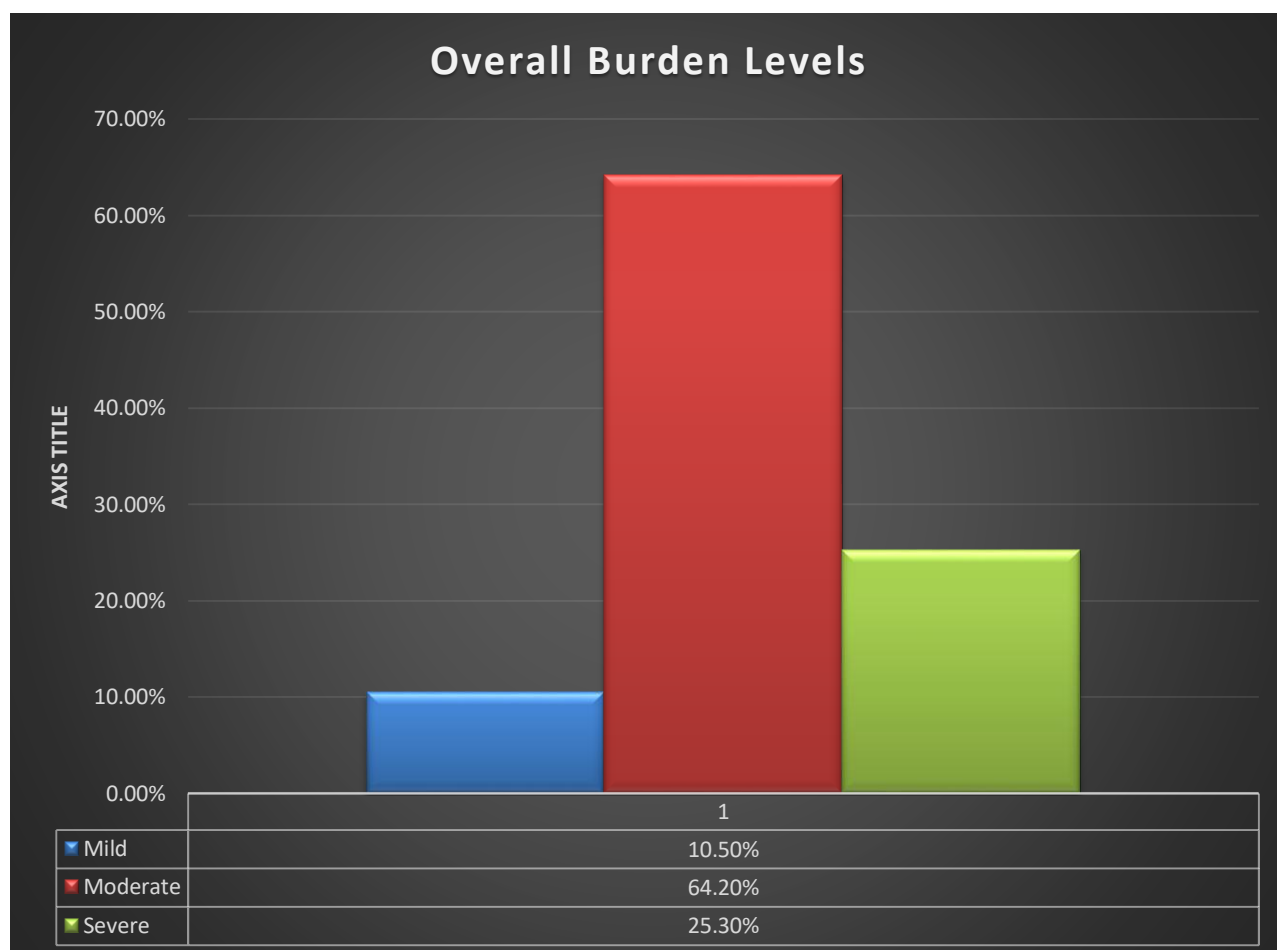


Fig (4.1) Overall Burden Levels

The overall burden was at a moderate level for most of participants (n = 61; 64.2%), followed the severe level (n = 24; 25.3%), and the mild level (n = 10; 10.5%).

Table 2. Correlations between variables in the study.

Items	1.	2.	3.	4.	5.	6.
1. Caregiver' age	-					
2. Child's age	.242*	-				
3. Psychological Burden	-.109	.056	-			
4. Social Burden	-.194	.043	.652**	-		
5. Financial Burden	-.062	.160	.595**	.669**	-	
6. Overall Burden	-.136	.082	.945**	.834**	.780**	-

* The correlation is statistically significant at the 0.05 level., ** The correlation is statistically significant at the 0.01 level.

There is no association between the age of the caregiver and the age of the child, or between the sub-areas and the overall burden.

Table 3. Relationship between burden of caregivers with gender

	Ranks				Mann-Whitney	asymp sig
	Caregiver's Gender	N.	Mean Rank	Sum of Ranks		
Psychological Burden	Male	39	49.15	1917.00	1047.000	.733
	Female	56	47.20	2643.00		
	Total	95				
Social Burden	Male	39	53.05	2069.00	895.000	.134
	Female	56	44.48	2491.00		
	Total	95				
Financial Burden	Male	39	52.59	2051.00	913.000	.172
	Female	56	44.80	2509.00		
	Total	95				
overall Burden	Male	39	51.13	1994.00	970.000	.356
	Female	56	45.82	2566.00		
	Total	95				

Male caregivers experience greater psychological burden than female caregivers. There is, however, no statistically significant difference between the groups in the psychological burden between caregiver's gender groups. Male caregivers experience greater social burden than female caregivers. There is, however, no statistically significant difference between the groups in the social burden between caregiver's gender groups. Male caregivers experience greater financial burden than female caregivers. However, there is, however, no statistically significant difference between the groups in the financial burden between caregiver's gender groups. Male caregivers experience greater overall burden than female caregivers. The overall load is not significantly different between caregiver gender categories.

Table 4. Relationship between burden of sample with groups of child's gender

	Ranks				Mann-Whitney U	Asymp. Sig.
	Child's gender	N	Mean Rank	Sum of Ranks		
Psychological Burden	Male	54	51.05	2756.50	942.500	.216
	Female	41	43.99	1803.50		
	Total	95				
Social Burden	Male	54	51.08	2758.50	940.500	.208
	Female	41	43.94	1801.50		
	Total	95				
Financial Burden	Male	54	51.69	2791.50	907.500	.131
	Female	41	43.13	1768.50		
	Total	95				
Overall Burden	Male	54	51.21	2765.50	933.500	.192
	Female	41	43.77	1794.50		
	Total	95				

Male caregivers are more stressed than female caregivers. Stress is similar across gender groups in children. Child caregivers suffer a greater societal cost than mothers. The social load is similar across child gender groups. Male child caregivers bear more financially. The financial cost is similar across child gender groups. Male caregivers suffer more than female caregivers. No substantial differences exist between the child gender groups.

Table (5). Relationship between Burden among caregiver's level of education

Ranks				Chi-square	df	Asymp. Sg.
	Caregiver's level of Edu.	N	Mean Rank			
Psychological Burden	Incapable of reading and writing	3	50.83	6.616	6	.358
	Reads and writing	8	59.69			
	Primary school	21	49.14			
	Graduate of a middle school	24	52.83			
	Graduate of high school	20	46.48			
	Institute/College	17	34.50			
	Graduate Degree	2	57.00			
	Total	95				
Social Burden	Incapable of reading and writing	3	56.00	14.545	6	.024
	Reads and writing	8	67.25			
	Primary school	21	45.86			
	Graduate of a middle school	24	58.67			
	Graduate of high school	20	43.10			
	Institute/College	17	32.47			
	Graduate degree	2	34.50			
	Total	95				
Financial Burden	Incapable of reading and writing	3	46.83	4.421	6	.620
	Reads and writing	8	54.81			
	Primary school	21	46.02			
	Graduate of a middle school	24	56.19			
	Graduate of high school	20	43.45			
	Institute/College	17	41.06			
	Graduate Degree	2	49.50			
	Total	95				
Overall Burden	Incapable of reading and writing	3	50.83	10.567	6	.103
	Reads and writing	8	64.00			
	Primary school	21	48.10			
	Graduate of a middle school	24	55.71			
	Graduate of high school	20	45.30			
	Institute/College	17	31.97			
	Graduate Degree	2	49.50			
	Total	95				

Caregivers who read and write endure a bigger psychological load than those with a college degree, those who graduated from middle school, those who could not read or write, those who graduated from primary school, those who graduated from high school, and those who graduated from college/college. There were, however, no significant variations in psychological load between careers with varying levels of education. Caregivers who can read and write suffer a bigger societal responsibility than those who did not graduate from middle school, those who did not graduate from elementary school, those who graduated from high school, those with an undergraduate degree, and those who graduated from institute/college. Between caregiver education groups, there is a statistically significant difference in social load (Chi-square = 14.545, $df = 6$, $p\text{-value} = .024$). Caregivers who graduated from middle school suffer a bigger financial burden than can read and write, those with a college degree, cannot read or write, those who graduated from elementary school, high school, or institute/college. However, there is, however, no statistically significant difference between the groups in financial hardship between the educated groups' careers. Caregivers who read and write suffer a greater total load than those who graduated from middle school, those who were unable to read or write, those with a graduate degree, those who graduated from elementary school, high school, or postgraduate institute/college. However, there were no significant variations in total burden between careers with varying levels of education.

Table (6): Relationship between the burden of sample study and residency area

	Ranks				Mann-Whitney U	Asymp. Sig.
	Residency	N	Mean Rank	Sum of Ranks		
Psychological burden	Urban	89	46.44	4133.00	128.000	.033
	Rural	6	71.17	427.00		
	total	95				
Social Burden	Urban	89	46.74	4160.00	155.000	.085
	Rural	6	66.67	400.00		
	Total	95				
Financial Burden	Urban	89	46.31	4121.50	116.500	.020
	Rural	6	73.08	438.50		
	Total	95				
Overall Burden	Urban	89	46.34	4124.00	119.000	.023
	Rural	6	72.67	436.00		
	Total	95				

Rural residents face a bigger psychological strain than urban residents. Psychological burden is significantly different between accommodation groups (Mann-Whitney U = 128.000, $p\text{-value} = .033$). Rural residents face a bigger social burden than urban residents. However, there is, however, no statistically significant difference between the groups in social burden between dwelling categories. Rural residents face a bigger financial burden than urban residents. Financial burdens differ significantly between housing groups (Mann-Whitney U = 116.500, $p\text{-value} = .020$). Rural residents bear a bigger overall burden than urban residents. The overall load is statistically significantly different between residence groups (Mann-Whitney U = 119,000, $p\text{-value} = .023$).

4. Discussion

Characteristics of the Caregivers the results of the study reported that the participants' sociodemographic

characteristics, the caregiver's age mean was (29-38, 40%) year, the child's age were group of (3-4, 35.8%) years old. Furthermore, more than a half were males (56.8%), The illness was moderate in severity for more than a half of children (53.7%), Less than a half of caregivers were mothers of ill children (47.4%), Concerning caregivers' educational level, around a quarter were middle school graduates (25.3%), Regarding caregivers' occupation, around a half were out of job (50.5%), Ultimately, the clear majority of caregivers reported that they live in urban areas (93.7%), The overall burden was at a moderate level for most of participants (64.2%).

Education for careers of children with cerebral palsy enhances quality of life and minimizes stress. The physical, psychological, and environmental social components of WHOQOL-BREF showed no Change that is statistically significant (p value > 0.05). It furthermore demonstrates statistically significant results (p -value 0.05). The quality of life for children with cerebral palsy may improve with caregiver education [1].

4.1 Relationship between Demographic of study sample and burden of caregivers

There is no correlation between caregiver's age, child's age, and each of the sub domains and the overall burden [8].

4.2 Relationship between Burden of study sample and Gender of caregivers

Mentally, male caretakers are burdened more than female caregivers Caregiving males face larger social cost. Male caregivers have higher financial challenges. Male carers are burdened more than female caregivers. the result backed up [6].

4.3 Relationship between Burden of study sample and Gender of children

Caregivers who care for the male children experience greater psychological burden than those who care for female children. Caregivers who care for the male children experience greater social burden than those who care for female children. Caregivers who care for the male children experience greater financial burden those who care for female children. Caregivers who care for the male children experience greater overall burden than those who care for female children. The study support by [14].

4.4 Relationship between Burden of study sample and level of education

Caregivers who read and write face a greater psychological burden than those with a college degree, a greater social burden than those who graduated from middle school, and a greater financial burden than those read and write. Overall, caregivers are read and write face a greater burden than those who graduated from middle school [4].

4.5 Relationship between Burden of study sample and Residency

Participants who live in rural areas face a greater psychological burden than those who live in urban areas, a greater social burden than those who live in urban areas, a greater financial burden than those who live in urban areas, and a greater overall burden than those who live in urban areas. (Table 7). The results remained that the most of the sample were in the age of (29- 38) years, child's age were group of (3- 4), most of them male (56.8%), the illness was moderate in severity for more than a half of children (53.7%), caregivers' level of education were middle school graduates (25.3%), majority of caregivers they live in urban areas (93.7%). The study reveals that burden between Caregiver's genders were mostly male because they experience more psychological, social and financial than female. The study agree by [10]. In 2014, an observational research was conducted to assess the quality of life of children with CP. 100 CP moms were studied. The study was done by Erbil's Helena Center for Disabled Kids. A two-part questionnaire was utilized to collect data. Demographics of mothers were studied first, then children with cerebral palsy. SPSS 18 was used to examine data from the second section of the questionnaire. It was used to test for association and significance. Most

were poor, urban, aged 28-37, and had kids. Males 2-4 years old with spastic cerebral palsy dominated. Cerebral palsy types were linked to daily activities, discomfort, and speech. Communication, eating, and activities had P values of 0.032, 0.000, 0.011, 0.014. The study recommended that women attend specific health education sessions to aid their children with cerebral palsy [3].

5. Conclusion

Burden among severity of illness groups were more of caregivers' psychological, social and financial burden than moderate or mild illness.

Recommendation: Pamphlet or booklet should be designed and distributes for caregiver how to deal with children cerebral palsy.

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Data availability statement: The corresponding author will share data supporting the study conclusions upon reasonable request.

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