

Psychosocial Burden among Mothers of Cerebral Palsy Children

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Abstract

Background: Cerebral palsy is a complicated social problem that affects society in general and families in particular, and no parent wants to infect one of their children with illness or handicap. Caregivers, particularly mothers of children with cerebral palsy, are subjected to a significant psychosocial strain. The researchers wanted to see if there was a link between mothers' psychosocial stress and their children's quality of life. This study aimed to assess psychosocial burden among mothers of cerebral palsy children in Babylon Province/ Iraq. **Methods:** A cross-sectional study was conducted on a sample of 150 mothers who had child's with cerebral palsy. A non-probability sampling strategy was used to choose a purposive sample of 150 mothers. According to the Babel Health Directorate, this sample was given to two hospitals, including (Imam AL-Sadiq Hospital and Babylon Rehabilitation Centre). The reliability of the questionnaire was achieved through a pilot study and then presented to experts to prove its validity. The total number of items included in the questionnaire was 20-items. The data was collected by using the semi-structured interview and analyzed by the application of descriptive and inferential statistical data analysis approach. **Results:** According to the findings, (49.3%) of mothers experienced a high level of psychological burden, (68.7%) experienced a high level of social burden. There are statistically significant differences between psychosocial burden and sociodemographic characteristics of mothers, such as age, education level, occupation, income, housing area, number and type of family ($p < 0.05$). **Conclusions:** Mothers expressed a high level of psychological burden as being a risk for psychiatric morbidity Because cerebral palsy is considered an additional stress factor for the family, and psychological burden mostly arises during acute events, and the chronicity of the condition predisposes these mothers to psychological depression. One of the key aims for minimizing the stress on mothers of impaired children is to design therapeutic programs to lessen psychological burden in parents of children with cerebral palsy.

Keywords: Psychosocial, Mothers, Cerebral Palsy.

1. Introduction

Cerebral Palsy (CP) is a long-term disability caused by persistent injury to the developing brain. CP is a big contributor to children's poor health. Although the Centers for Disease Control and Prevention (CDC) study indicated that the average prevalence of CP in 2004 and 2008 was 3.3 per 1000 live births and 3.1 per 1000 8-year-old children, respectively [1, 2], the incidence of CP varies greatly across geographical zones. Boys had a much higher incidence than girls (male/female ratio of 1.4:1) [3]. Spastic paralysis, cognitive impairment, chronic pain, speech and vision impairment, and gastrointestinal and eating disorders are just some of the issues that a kid with CP faces [4]. They also have a number of self-care constraints, including feeding, dressing, bathing, and mobility [5, 6]. These limits can lead to a need for long-term care that is substantially greater than that of typical children [7]. The difficulties that children with CP confront cause their parents to be more stressed [8], which has a negative impact on their physical health and social well-being [9].

The relationship between a person and their social environment, as well as the influence on their behavior, is referred to as psychosocial [10]. Family members, friends,

coworkers, employers, the compensation system, and health professionals are all part of the social environment [11]. As a result, psychosocial issues are issues that affect a person's social environment [12]. It is critical to recognize and treat the psychological challenges that caregivers of afflicted children face in order to build a family-centered care practice [13]. In research from western cultures, parents of children with Cerebral Palsy have been documented to have a variety of psychosocial issues [14]. Therefore, this study aimed to assess psychosocial burden among mothers of cerebral palsy children in Babylon Province/ Iraq.

2. Methodology

A cross-sectional study was conducted on a sample of 150 mothers of cerebral palsy is selected purposively. These sample is distributed throughout two rehabilitative centers in Hilla City/ Babylon Province.

Study instrument: The questionnaire is one of the means to help collect data that contribute to achieving the results expected by the study, so the researcher designed this questionnaire, which aims to clarify the study objectives and significance by obtaining answers to the study's questions.

This questionnaire consists of two for parts which includes the following:

Part I: This section composed of socio-demographic information which include mothers age, education, occupation, income, number of family and type of family. Part II: This part is about psychological burden, and the researcher used and produced an evaluation method to measure it among moms of children with CP. The following are some of the tools available:

- ☒ Psychological burden: This consisted of 31-items that were rated and scored 1× always, 2× sometime, and 3 × never on a three-level Likert rating scale.
- ☒ The social burden is made up of 18-items that are measured on three levels. They have been rating and scoring 1 × always, 2 × sometime, and 3 × never using a Likert rating scale.

Validity was given to a arbitrators were asked to offer their opinions and suggestions on each of the study questionnaire's components in terms of language appropriateness, association with the dimension of study variables to which it was assigned, and suitability for the study population. To assess the questionnaire's reliability, data were collected from nurses, and the test was administered to 10 subjects from the study population who were not part of the original sample. Cronbach's alpha was discovered to be 0.83.

The SPSS ver-20.0 software application was used to conduct statistical analysis (SPSS). The information was evenly distributed. One-way analysis of variance and independent sample *t test* were used to examine variations in variables based on socio-demographic characteristics. For continuous variables, descriptive data is reported as mean standard deviation, and for categorical variables, it is shown as number (percent). Statistical significance was defined as a *p* 0.05.

3. Results

Table (4-1) show participants age, the mean age is 28.79+7.661, at age group 20-24 years old (*n*=43; 28.7 %). Respect to the education, findings show the read and write was predominated (*n*=82; 54.7 %). In regards with occupation, findings show that the unemployed mothers were records the highest percentage (*n*=116; 77.3 %). In terms of monthly income, the mothers express is not enough income (*n*=70; 46.7 %). Housing area related findings, most of mothers countryside residents (*n*=68; 45.7 %). Number of family member, most of families constituted from 4 to 5 member (*n*=67; 44.7 %). Type of family, the extended families were records the highest percentage (*n*=92; 61.3 %).

	Classification	Freq.	%
Age/years (M + SD= 28.79+7.661)	<20 years old	11	7.3
	20-24 years old	43	28.7
	25-29years old	30	20.0
	30-34years old	30	20.0
	35-39 years old	21	14.0
	≥40 years old	15	10.0
Education Level	Do not read or write	28	18.7

	Read and write	82	54.7
	Secondary	21	14.0
	Institutes and more	19	12.7
Occupation	Employ	34	22.7
	Unemployed	116	77.3
Monthly income	Enough	47	31.3
	Certain limit enough	33	22.0
	Is not enough	70	46.7
Housing area	Countryside	68	45.3
	Outskirts	35	23.3
	City	47	31.3
Number of family member	<4	28	18.7
	4-5	67	44.7
	>5	55	36.7
Type of family	Nuclear	58	38.7
	Extended	92	61.3

Findings illustrated that the (49.3%) of mothers who have cerebral palsy children expressed a high level of psychological burden (M ± SD=50.06±10.830).

Psychological Aspects	Freq.	%	M ± SD
High	74	49.3	50.06 ± 10.830
Moderate	70	46.7	
Low	6	4.0	
Total	150	100.0	

Findings demonstrated that the (68.7%) of mothers who have cerebral palsy children expressed a high level of social burden (M ± SD=29.08±6.803).

Social Aspects	Freq.	%	M ± SD
High	103	68.7	29.08 ± 6.803
Moderate	37	24.7	
Low	10	6.7	
Total	150	100.0	

Age	Source of variance	Sum of Squares	d.f	Mean Square	F	<i>p</i> ≤ 0.05
Psychosocial Burden	Between Groups	2.840	5	.568	12.130	.000
	Within Groups	6.742	144	.047		
	Total	9.582	149			

Findings demonstrated that there were highly significant differences in psychosocial burden with regard mothers age (*p*=0.000) (Fig.1).

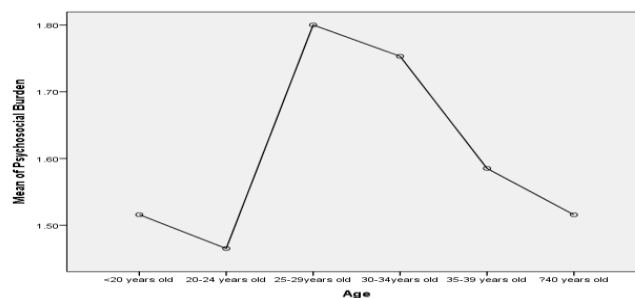
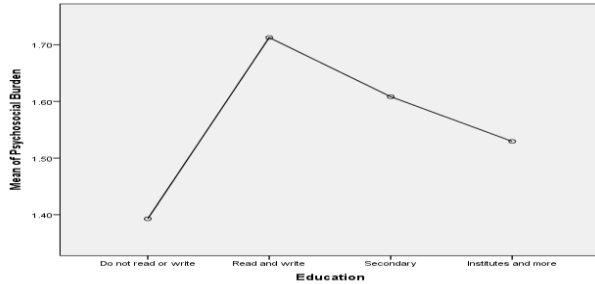


Table 5. Significant Differences in Psychosocial Burden with regards Mothers Education

Education Level	Source of variance	Sum of Squares	d.f	Mean Square	F	$p \leq 0.05$
Psychosocial Burden	Between Groups	2.306	3	.769	15.420	.000
	Within Groups	7.277	146	.050		
	Total	9.582	149			

Findings demonstrated that there were highly significant differences in psychosocial burden with regard mothers education ($p=0.000$) (Fig. 2).



differences in psychosocial burden with regard mothers housing area ($p=0.000$) (Fig. 4).

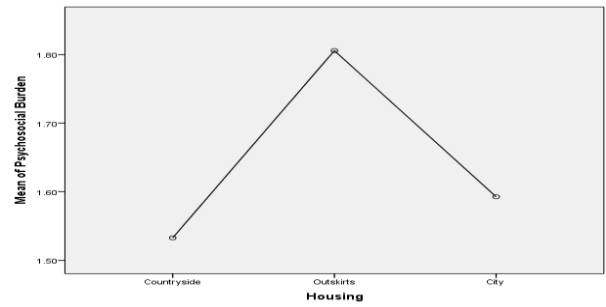


Table 9. Significant Differences in Psychosocial Burden with regards Mothers Number of Family Member

No. Family	Source of variance	Sum of Squares	d.f	Mean Square	F	$p \leq 0.05$
Psychosocial Burden	Between Groups	1.430	2	.715	12.897	.000
	Within Groups	8.152	147	.055		
	Total	9.582	149			

Findings demonstrated that there were highly significant differences in psychosocial burden with regard number of family members ($p=0.000$) (Fig. 5).

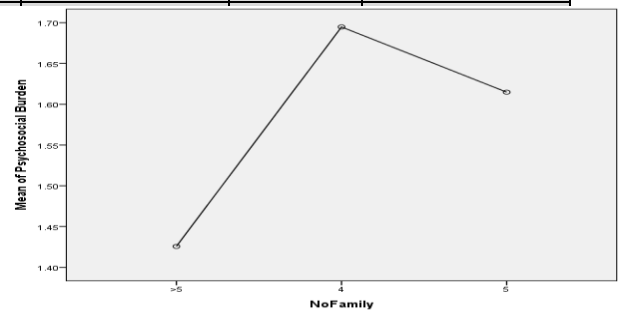


Table 6. Significant Differences in Psychosocial Burden with regards Mothers Occupation

Psychosocial Burden	Occupation	Mean	S.D
Psychosocial Burden	Employ	1.4130	.27601
	Unemployed	1.6745	.21406

Findings demonstrated that there were highly significant differences in psychosocial burden with regard mothers occupation ($p=0.000$).

Table 7. Significant Differences in Psychosocial Burden with regards Mothers Income

Income	Source of variance	Sum of Squares	d.f	Mean Square	F	$p \leq 0.05$
Psychosocial Burden	Between Groups	2.342	2	1.171	23.773	.000
	Within Groups	7.240	147	.049		
	Total	9.582	149			

Findings demonstrated that there were highly significant differences in psychosocial burden with regard mothers income ($p=0.000$) (Fig. 3).

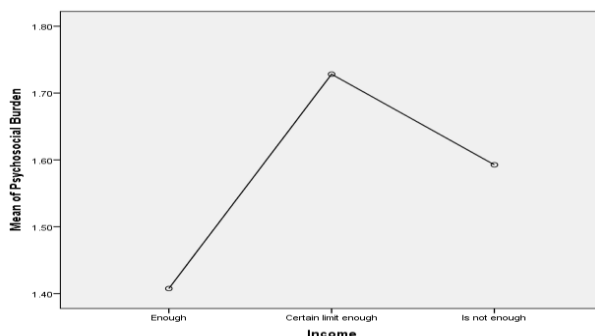


Table 8. Significant Differences in Psychosocial Burden with regards Mothers Housing Area

Housing	Source of variance	Sum of Squares	d.f	Mean Square	F	$p \leq 0.05$
Psychosocial Burden	Between Groups	1.758	2	.879	16.519	.000
	Within Groups	7.824	147	.053		
	Total	9.582	149			

Findings demonstrated that there were highly significant

Table 10. Significant Differences in Psychosocial Burden with regards Type of Family

Psychosocial Burden	Type of family	Mean	S. D	t-value	d.f	$p \leq 0.05$
Psychosocial Burden	Nuclear	1.4870	.25046	5.536	148	.000
	Extended	1.6961	.22116			

Findings demonstrated that there were highly significant differences in psychosocial burden with regard type of family ($p=0.000$).

4. Discussion

Parents (mothers) are always at the center of management, taking an active role in all phases of cerebral palsy therapy and care. Evidence suggests that involving mothers in the physical therapy process reduces the time it takes to achieve therapeutic goals in children with physical disabilities. The family plays a crucial role in the management of cerebral palsy in children, which places psychological and social strains on the family [15]. Mothers of children with cerebral palsy, in particular, face a significant psychosocial strain. However, in low- and middle-income countries, documentation of the diverse sources of stress is scarce. The majority of studies on children with cerebral palsy concentrated on the disease itself, leaving the family side

mostly unexplored. Only a few research on the psychological burden were found in our search. The mothers were asked to answer 31 questions about psychological stressors. According to the results of the current study, mothers of children with cerebral palsy experienced a high level of psychological distress ($M \pm SD = 50.06 \pm 10.830$). Through the results obtained after the statistical treatment of the data, it was found that the percentages of the distribution of degrees. The psychological burden of the study sample was as follows: The proportion of mothers with high psychological burden was 49.3%. The proportion of mothers with moderate psychological burden was 46.7%. The proportion of mothers with low psychological burden was 0.4%.

This conclusion, in our opinion, emphasizes the societal perspective of families with cerebral palsy children held by community members, putting additional pressure on them, particularly the mother, who carries the obligation of caring for this child. Furthermore, mothers who are preoccupied with the needs of the rest of the family and household chores may be deprived of performing their societal duties, leading them to isolate, neglect themselves, and ignore their rights. As a result, their psychological condition deteriorates, and they become vulnerable to a variety of diseases. Similarly, in a study by Yilmaz et al., 2013, the stress level in mothers of children with Konya cerebral palsy was higher than in control mothers with healthy children, owing to psychological burden that arises mostly during acute events and the chronicity of the condition predisposes these mothers to psychological depression [16]. Despite the fact that cerebral palsy is regarded as an additional source of stress for families, research on the subject is limited. Mobarak et al. [17], reported that 41.8 percent of the 91 mothers of children with cerebral palsy in Bangladesh were at risk for psychiatric illness due to substantial psychological burdens [17]. Another study, conducted by Brehaut et al. [18], found that main carers of children with cerebral palsy experienced more psychological and physical symptoms than the control group, owing to the mothers' embarrassment and low self-esteem [18]. In a study looking into the psychological well-being of mothers with cerebral palsy children, it was discovered that the majority of mothers had depressed symptoms [19]. Degree of impairment, sadness, and self-efficacy were the most important indicators of caregiver strain. As a result, research suggest that one of the key goals of minimizing the stress on caregivers of disabled children should be to create therapies to minimize sadness and increase self-efficacy in parents of children with CP [20]. Acute occurrences occur frequently, and the chronicity of the illness predisposes these mothers to psychological distress. It's likely that mothers had anxiety symptoms at the time of diagnosis, but that these symptoms were transformed into or replaced with depressive symptoms, resulting in psychological distress. More research is needed to assess the needs and concerns of mothers who have children with cerebral palsy [21]. While attempting to improve her child's quality of life, the mother caring for the cerebral palsy youngster may jeopardize her own. It's

important to remember that mothers, who are typically the primary caretakers for children with cerebral palsy, play an important role throughout the treatment process, and that without their help, treatment would not be as effective [22]. When making treatment decisions, health professionals working in the field of cerebral palsy and particular needs should also consider the mothers' psychological status and quality of life.

The mothers were quizzed on 18 social burdens-related questions. The mothers in the current study exhibited a significant level of social burden ($M \pm SD = 29.08 \pm 6.6803$). The percentages of the distribution of degrees were discovered using the results acquired following statistical treatment of the data. The study sample's social burden was as follows: The proportion of mothers with high social burden was 68.7%. The proportion of mothers with moderate social burden was 24.7%. The proportion of mothers with low social burden was 6.7%. This result, in our opinion, clarifies the lack of social support and the support that the mother desperately requires, which may contribute to the high perceived social burden among mothers, as well as a lack of sufficient information on the issue of cerebral palsy, leaving the mother perplexed about how to deal with her disabled son. These findings are supported by Michael et al. [23], who discovered that mothers of children with cerebral palsy face major social issues that are frequently disregarded by the general population due to the following factors. (1) the stress of caring for a child who is overly reliant; (2) limiting mothers' participation in society; (3) financial constraints faced by mothers of children with cerebral palsy; (4) health issues faced by mothers of children with cerebral palsy; (5) uncertainty about the child's future; (6) society's negative perception of the child's problems [23]. In the same vein, a qualitative study in India of psychosocial stress among mothers of children with cerebral palsy found that the main issues were the mothers' disturbed social relationships, health problems, financial problems, worry about the child's future, and a need for more supportive services [24]. A similar Iranian study found very similar stressors as well as harsh and unsupportive contacts with society, due to a lack of support from their husband and family in the care-giving process, as well as little assistance from community members, all of which contributed to feeling separated from others [25]. This could be because mothers feel aches and pains as a result of the high physical activity of caring for their children. They also have a sense of remorse for the child's situation. They faced substantial societal costs as a result of their inability to balance family and career. They also have a lack of understanding and awareness regarding their child's therapy alternatives [26]. The mothers lacked assistance from their husbands and families on a personal level. They also had to deal with the consequences of their husbands' drunkenness and physical violence. They had to make sacrifices in terms of the attention they gave to their family members and children. cerebral palsy is a condition that affects the brain [20].

There were extremely significant differences in psychological burden with reference to mothers' age ($p=0.000$), according to the findings. Mothers aged 20-24

years old, on the other hand, have a much higher psychosocial burden (fig. 1). According to the findings, one of the elements that contributes greatly to the disparity in the amount of psychological burden that is exposed is the mother's age. According to Singh et al. [27], mothers' burden grows as their age (under 30 years) diminishes, and their ability to endure burden reduces. When the burdens of a disabled child are added, the experience of psychosocial stress is likely to escalate [27]. Younger mothers, on the other hand, face their kid's handicap early in life and have no experience raising a disabled child, making them more vulnerable. A sense of surprise and dissatisfaction, and hence those reasons for the younger age groups, may have made them more burdensome.

There were extremely significant differences in psychological burden with reference to mothers' education ($p=0.000$), according to the findings. The findings suggest that educational levels have an effect on the levels of psychosocial burden among mothers of children with cerebral palsy, since the burden does not appear to be equal at all educational levels. Those who cannot read or write, on the other hand, face a substantially higher psychosocial burden since they do not know how to properly seek treatment (fig. 2), making them distinct from both the educated and the uneducated. The presence of disparities in perceived pressure among mothers of mentally impaired children suggests that the woman who can read and write (average educational level) may be under pressure as a result of her child's impairment. Due to her annoyance and grumbling about her son's illness, and the way she interprets the stressful scenario or incident she was exposed to, her personality pattern has changed [14].

There were extremely significant differences in psychological burden with reference to mothers' occupation ($p=0.000$), according to the findings. According to these findings, which agree with those of Issa and Mohammed (2016), a mother's occupation is substantially associated with her burden ($p=0.05$), and mothers who are employed have a higher level of psychosocial burden than mothers who are jobless [28, 29]. According to our findings, people who are employed ($M\ SD=1.67\pm 0.214$) have a much higher psychological burden than those who are unemployed ($M\ SD=1.41\pm 0.276$). due to the fact that a working mother is looking for a remedy for her untreated child's condition.

There were extremely significant differences in psychological burden with reference to mothers' income ($p=0.000$), according to the findings. Those with a sufficient monthly income, on the other hand, have a substantially higher psychosocial burden (fig. 3). They engage in more therapeutic research for their children than those who do not have enough money. Cheshire et al. (2010) discovered that a high or moderate monthly income was connected with a high level of psychological stress in children with cerebral palsy [30]. The considerable discrepancies can be related to the lack of comparability in the circumstances of these families in terms of the health issues they face, which are unique to the challenged child, as well as other economic issues that

cause them to differ in the degree of stress they experience.

There were extremely significant differences in psychosocial burden with relation to mothers' living area ($p=0.000$), according to the findings. Those who live in the countryside, on the other hand, face a substantially higher psychosocial burden due to the distance between them and health care providers (fig. 4). In this regard, the findings of Sternal et al. [31], who stated that due to the constraints of health facilities, mothers residents' burden connected to cerebral palsy children had been influenced [31].

The results revealed that the number of family members had a significantly significant impact on psychosocial burden ($p=0.000$). Those with more than five family members, on the other hand, have a much higher psychosocial burden (fig. 5). The more family members there are, the more burdens the mother bears, as she is accountable for all of them. The number of family members and the duty for caring for their children with cerebral palsy varied significantly. The mother's psychological and social state deteriorates as a result of the huge number of family members [32].

There were extremely significant differences in psychological burden based on family type ($p=0.000$), according to the findings. The psychological strain is much higher in nuclear families ($M\ SD=1.48\pm 0.25046$) than in extended families ($M\ SD=1.69\pm 0.221$). The disparity can also be attributed to a lack of awareness of disability and how to deal with and coexist with these children in extended families, as understanding and comprehending the reality of disability requires special knowledge and skills between families, as well as a lack of similarity in the circumstances of those families with regard to the special health problems they are exposed to. with a child that is disabled.

Study Limitation

Lack of national studied underlying of study.

5. Conclusion

Mothers expressed a high level of psychological burden as being a risk for psychiatric morbidity Because cerebral palsy is considered an additional stress factor for the family, and psychological burden mostly arises during acute events, and the chronicity of the condition predisposes these mothers to psychological depression. One of the key aims for minimizing the stress on mothers of impaired children is to design therapeutic programs to lessen psychological burden in parents of children with cerebral palsy.

Study Suggestion

When making treatment decisions, health experts working in the field of cerebral palsy should also consider the mothers' psychological condition and quality of life, as well as developing psychological sponsorship programs to assist them in dealing with their children's predicament.

Financial disclosure

There is no financial disclosure.

Conflict of interest

None to declare.

Ethical Clearance

All experimental protocols were approved by the Babylon Health Directorate in Iraq, and all experiments followed the permitted procedures.

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