Research Paper

Psychosocial Burden and Its Relationship to the Quality of Life (QoL) of Children With Cerebral Palsy: A Mothers' Feedback

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Citation Nadhim Suhib R, Hashim Mohammed S. Psychosocial Burden and Its Relationship to the Quality of Life (QoL) of Children With Cerebral Palsy: A Mothers' Feedback. Iranian Rehabilitation Journal. 2022; 20(2):261-270. http://dx.doi.org/10.32598/irj.20.2.1791.1

doi http://dx.doi.org/10.32598/irj.20.2.1791.1

Article info:

Received: 01 Jan 2022

Accepted: 10 Apr 2022

Available Online: 01 Jun 2022

ABSTRACT

Objectives: To investigate the psychosocial burden on mothers and its relationship to the Quality of Life (QoL) of children with cerebral palsy living in Babylon Province, Iraq.

Methods: This research is a descriptive correlational study. A non-probability sampling method was used to choose a sample of 150 mothers who had children with cerebral palsy. According to the Babel Health Directorate, this sample was recruited from two hospitals: Imam AL-Sadiq Hospital and Babylon Rehabilitation Centre. The reliability of the study questionnaire was achieved through a pilot study and then presented to experts to prove its validity. The total number of items included in the study questionnaire was 20 items. The data were collected by using semi-structured interviews and analyzed by the application of descriptive and inferential statistics.

Results: According to the findings, 49.3% of mothers experienced a high level of psychological burden, 68.7% a high level of social burden, and 92% experienced a low QoL for their cerebral palsy children. The QoL for cerebral palsy children was significantly correlated with mothers' psychosocial burden (r=-0.142; P=0.012).

Discussion: Mothers expressed a high level of psychological burden as a risk for psychiatric morbidity because of the burden of care, which leads to a relative reduction or stimulation of parents' demands. Mothers' psychosocial burdens are highly associated with their children's QoL. More research is needed to assess the requirements and concerns of families with CP children.

Keywords:

Psychosocial, Mothers, Cerebral Palsy, Quality of Life

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Highlights

- Most mothers exhibited a high psychological burden as described by low mean and standard deviation.
- Most mothers exhibited a poor quality of life (QoL) among cerebral palsy children.
- The high psychological burden negatively influenced the physical, emotional, social, and school functioning of cerebral palsy children.

Plain Language Summary

The loss of physical integrity has devastating effects on a person's mental and emotional as well as physical and social well-being. Evaluating the psychological burdens of such people can be done in various ways. Mothers of disabled people with cerebral palsy are greatly affected psychologically. Rehabilitation programs can often help the quality of life and psychological aspects of caregivers. Based on our study results, there is a negative relationship between psychological burdens and their impact on children's quality of life (QoL).

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1. Introduction

Cerebral palsy (CP) is characterized by impaired motor function, but many CP children also suffer sensory, linguistic, and intellectual deficits, as well as complex limitations in self-care duties. Caregiving is an expected aspect of being a parent of a small kid, but it takes on a whole new meaning when a child has functional limitations and requires long-term assistance [1]. One of the most challenging tasks for parents is to adequately manage their child's chronic health problems while managing the demands of daily life, too. As a result, caring for a kid with multiple disabilities at home can be a challenging task for caregivers. The provision of such care may adversely impact the physical and emotional health of parents [2].

Caring for any child requires significant resources, but the demands on these resources are typically multiplied when caring for a disabled child. Children with CP have been reported to suffer psychological issues, adding to the care load [3]. It has been demonstrated that the prevalence of speech impairments in children with CP significantly impacts mothers' depression levels [4]. It is unclear why some caregivers cope successfully while others do not. Even as the child's rehabilitation improves, it is necessary to monitor the caregiver's mental health regularly [3]. Parents of children with CP are more likely than other parents to be stressed [5]. According to one study, a disabled kid's reliance on others in daily tasks significantly impacts the mother's psychological discomfort, and the more reliant the child is, the more distressed the mother becomes [6].

Managing the psychosocial impacts of CP can be challenging because CP requires long-term care. Increased caregiving obligations, low maternal education, and ethnic background all impact cerebral palsy and parenting stress. As a result, coping techniques should focus on relieving the stress of everyday care, reducing hospital readmissions, and providing appropriate psychosocial support to specific subgroups of parents to modify parental perceptions and expectations [7]. In Babylon Province, Iraq, mothers of children with CP face unique challenges, such as the combination of gender norms, poverty, stigmatization, a lack of support, and non-inclusive public policy. They must be addressed to improve the quality of life (QoL) for both children and their caregivers. This study aimed to investigate the psychosocial burden on mothers and its relationship to the QoL of CP children in Babylon Province, Iraq.

2. Materials and Methods

A descriptive correlational study was conducted on a sample of 150 mothers of CP children. The mothers were selected purposively. This sample was collected from two rehabilitative centers in Hilla City, Babylon Province, Iraq.

Study tools

The researchers designed the study questionnaire, which aims to clarify the study objectives and significance by obtaining answers to the study questions. The questionnaire consists of three parts:

Part 1 was composed of sociodemographic information, which includes mothers' age, education, occupation, income, number of families, and type of family.

Part 2 was about the psychological burden, and the researcher designed an evaluation method to measure the psychological burden among moms of children with CP. The psychological burden consisted of 31 items rated on a 3-point Likert-type scale (1=always, 2=sometimes, and 3=never). The social burden comprises 18 items scored on a 3-point Likert scale 1=always, 2=sometimes, and 3=never).

Part 3 assessed the QoL for children with CP developed by Rasul et al. [8].

Validity and reliability

To check the instrument validity, a panel of experts was 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 mothers, and the test was administered to 10 subjects from the study population who were not part of the original sample. The Cronbach alpha was calculated to be 0.83 for psychological burden and 0.76 for children's QoL.

The SPSS software v. 20 was used to conduct statistical analysis. The study data were normally distributed. A correlation coefficient was used to associate between study variables. For continuous variables, descriptive data were reported as mean and standard deviation, and for categorical variables, it is shown as number and percentage. Statistical significance was defined as a P≤0.05.

3. Results

According to Table 1, the mothers' Mean±SD age was 28.79 (7.661) years, and the 20-24 years age group was the largest (n=43; 28.7%). Regarding education, most mothers could read and write (n=82; 54.7%). Concerning occupation, findings show that unemployed mothers comprised the highest group (n=116; 77.3%). In terms of monthly income, a large group of mothers expresses their insufficient income (n=70; 46.7%). Regarding the residential area, most mothers lived in the countryside (n=68; 45.7%). Also, most families comprised 4 to 5 members (n=67; 44.7%). Regarding the family type, the extended families had the highest percentage (n=92; 61.3%).

Findings demonstrated that 50.7% of mothers who have CP children expressed a high level of psychosocial burden (Mean±SD: 78.14±12.026).

Mothers reported the QoL for children with CP as 43.14±7.275; most mothers (n=138; 92.0%) expressed a poor QoL for their CP children.

There were significant correlations between the mother's burden and their children's QoL profiles: physical functions with mothers' burdens, r=-0.149 (P=0.058); emotional functioning, r=-0.187 (P=0.022); social functioning, r=-0.298 (P<0.000); and school performance, r=-0.186 (P<0.023). The QoL of CP children was significantly correlated with their mothers' psychosocial burden (r=-0.142; P=0.012).

4. Discussion

Parents, especially mothers, are always at the center of the management of CP and actively participate in all phases of CP therapy and care. Evidence suggests that involving mothers in the physical therapy process reduces the treatment time in children with physical disabilities. Although family plays a crucial role in managing CP in children, it puts psychological and social strains on the family [9]. Mothers of children with CP, in particular, face a significant psychosocial strain. However, in low- and middle-income countries, documentation of the diverse sources of burden is scarce.

Most studies on children with CP have concentrated on the disease, leaving the family side mostly unexplored. Only a few studies on the psychological burden were found in our search. We asked mothers to answer 31 questions about psychological burdens. According to our results, mothers of children with CP experienced a high psychological burden (Mean±SD: 50.06±10.830). The detailed results of the psychological burden of the study samples are as follows.

The proportion of mothers with a high psychological burden was 49.3%. The proportion of mothers with moderate psychological burdens was 46.7%, and the proportion of mothers with a low psychological burden was 0.4%. This conclusion, in our opinion, emphasizes the societal perspective of families with CP children held by community members, putting additional pressure on them, particularly the mothers, who carry the obligation of caring for these children. Furthermore, mothers preoccupied with the needs of the rest of the family and household chores may be deprived of performing their societal duties, leading them to isolation, neglecting themselves,

Table 1. Sociodemographic characteristics

Groups		No. (%)/Mean±SD
Age (y)	<20	11(7.3)
	20-24	43(28.7)
	25-29	30(20.0)
	30-34	30(20.0)
	35-39	21(14.0)
	≥40	15(10.0)
		28.79±7.661
Education Level	Cannot read or write	28(18.7)
	Read and write	82(54.7)
	Secondary	21(14.0)
	Institutes and more	19(12.7)
Occupation	Employed	34(22.7)
	Unemployed	116(77.3)
Monthly income	Enough	47(31.3)
	Hardly 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 members	<4	28(18.7)
	4-5	67(44.7)
	>5	55(36.7)
Type of family	Nuclear	58(38.7)
	Extended	92(61.3)

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and ignoring their rights. As a result, their psychological condition deteriorates, and they become vulnerable to various diseases. Similarly, in a study by Yilmaz et al., the burden level in mothers of children with Konya cerebral palsy was higher than in control mothers with healthy children, owing to the psychological burden that arises mainly during acute episodes and the chronicity of the condition predisposes these mothers to psychological depression [10]. Even though CP is considered an additional burden for families, research on the subject is limited. Mobarak et al. reported that 41.8% of the 91 mothers of children with CP in Bangladesh were at risk for psychiatric illness due to substantial psychological burdens [11]. Another study by Brehaut et al. found that the primary caregivers of children with CP experienced more psychological and physical symptoms than the control group, owing to the mothers' embarrassment and low self-esteem [3]. In a study on the psychological well-being of mothers with CP children, it was discovered that most mothers had depression symptoms [12].

Table 2. Psychosocial burden

Psychological Aspects	No. (%)	Mean±SD
High	76(50.7)	78.14±12.026
Moderate	72(48.0)	
Low	2(1.3)	
Total	150(100)	

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Table 3. QoL for children with cerebral palsy

QoL	Social Aspects	No.(%)	Mean±SD
Physical function	Poor	122(81.3)	16.48±5.005
	Moderate	21(14.0)	
	Good	7(4.7)	
Emotional function	Poor	118(78.7)	9.84±3.299
	Moderate	24(16)	
	Good	8(5.3)	
Social function	Poor	120(80)	8.88±4.763
	Moderate	28(18.7)	
	Good	2(1.3)	
School function	Poor	134(89.3)	7.92±4.464
	Moderate	15(10)	
	Good	1(0.7)	
Overall	Poor	138(92)	43.14±7.275
	Moderate	12(8)	

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Table 4. Correlation between mothers' psychosocial burden and their children's QoL

Mothers Burden	r	P
Physical	-0.149*	0.058
Emotional	-0.187*	0.022
Social	-0.298**	0.000
School	-0.186*	0.023
Total QoL	-0.142*	0.012

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Degree of impairment, sadness, and self-efficacy were the most critical indicators of caregiver strain. As a result, researchers suggest that one of the key goals of minimizing the burden on caregivers of disabled children should be to create therapies to minimize sadness and increase self-efficacy in parents of children with CP [13]. Acute episodes of CP occur frequently, and the chronicity of the illness predisposes these mothers to psychological burden. Mothers likely had anxiety symptoms at the time of diagnosis, but these symptoms were transformed into or replaced with depressive symptoms, resulting in a psychological burden. More research is needed to assess the needs and concerns of mothers who have CP children [14]. While attempting to improve her child's QoL, the mother caring for the CP youngster may jeopardize her life. It is important to remember that mothers, who are typically the primary caretakers for children with CP, play an essential role throughout the treatment process, and without their help, treatment would not be as effective [15]. When making treatment decisions, health professionals working in the field of CP should also consider the mothers' psychological status and QoL.

The mothers were asked 18 social burdens-related questions. The mothers in the current study exhibited a significant social burden (Mean±SD: 29.08±6.6803). The detailed study sample's social burden was as follows. The proportion of mothers with a high social burden was 68.7%. The proportion of mothers with moderate social burden was 24.7%, and the proportion of mothers with a low social burden was 6.7%. These results, in our opinion, clarify the lack of social support that the mothers desperately need, which may contribute to the high perceived social burden among mothers. Also, the insufficient information on cerebral palsy leaves mothers confused about how to deal with their disabled child. These findings are supported by Michael et al., who discovered that mothers of children with CP face major social issues frequently disregarded by the general population due to the following factors. The burden of caring for an overly reliant child, limiting mothers' participation in society, financial constraints faced by mothers of children with cerebral palsy, health issues faced by mothers of children with cerebral palsy, uncertainty about the child's future, and society's negative perception of the child's problems [16]. In the same vein, a qualitative study in India on psychosocial burden among mothers of children with CP 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 [17]. A comparable Iranian study found similar mothers' burdens and awkward contact with society due to a lack of support from their husband and family in the caregiving process, as well as little assistance from community members, all of which contributed to feeling separated from others [18]. This result could be because mothers feel aches and pains due to the high physical activity of caring for their children. They also have a sense of remorse for the child's situation. They face substantial societal costs due to their inability to balance family and career. They also lack understanding and awareness regarding their children's therapy alternatives [19]. The mothers receive no assistance from their husbands and families on a personal level. They also must deal with the consequences of their husbands' drunkenness and physical violence. They have to make sacrifices in terms of the attention they give to their family members and children. Cerebral palsy is a condition that affects the brain [20].

Due to a high level of psychosocial burdens, mothers of CP children express a poor QoL for their CP children in terms of physical, emotional, social, and school functions. Caregivers (mothers) show a lower QoL. Burden and depression are common among caregivers [13]. The mothers' burden and despair are negatively proportional to their level of self-efficacy and social support [21]. The increased hardship associated with larger functional limitations was decreased by seeking social assistance. Psychosocial interventions aimed at assessing and increasing social support for caregivers may benefit families at high risk of caregiver deterioration, reducing adverse outcomes and improving the QoL for both (mothers and children) [22]. Mothers' burdens for children with CP are often overlooked. In addition to the psychological issues mentioned above, the parents also experience social isolation, miss social activities, get stigmatized, and have disputes with their families and society. They also experience physical burdens, such as sleep deprivation, musculoskeletal aches and pains, and hypertension. As a result, this underappreciated phenomenon of caregiver burden must be acknowledged and treated.

According to the current study's findings, there were significant relationships between the mother's burden and the QoL profiles of their children. The QoL of CP children had been significantly correlated (reverse) to their mothers' psychosocial burden (r=-0.142; P=0.012). Previous research using the same variables found a link between the amount of psychosocial burden and the child's QoL in terms of emotional, social, and academic functions [23]. This last conclusion is in line with the current study's findings, which are based on the QoL and burden. This result shows that, in cerebral palsy instances, children's QoL from mothers' comments, which is a straightforward evaluation approach, may be a good indicator of the child's QoL. Furthermore, prior research that used the gross motor function classification system (GMFCS) revealed mixed results (a significant negative relationship between mothers' burden and their QoL-related physical function of children with cerebral palsy) [24]. Parents of children with CP, particularly mothers, might be negatively affected and face a lot of burdens [25]. Previous research has found that children with CP suffer significant levels of burden and sadness, as well as impaired QoL [26]. Nonetheless, caring for a kid with CP has been shown to positively impact a parent's life, indicating the family's adaptability [27]. However, it is unclear why some parents manage well with the challenges of caring for their children while others do not [2]. This difference could be due to the widespread medical comorbidities associated with cerebral palsy, which causes parents' demands to be reduced or stimulated. According to Parkes et al., 42% of parents with children with CP (who have psychological problems) indicated that they burdened the family quite a lot [28]. Other characteristics linked to a more significant caregiver burden include child behavior and cognitive issues, low caregiver self-efficacy, and a lack of social support [26]. Aside from these characteristics, the severity of the condition has been studied, and it has been discovered that milder problems are linked to better results for parents of children with CP [29]. Previous research and the current study's findings suggest that severe disability in children with CP is linked to a lower QoL and a greater burden on mothers. These data indicate that family-centered intervention strategies are increasingly replacing child-centered approaches [30]. Caregivers' psychological well-being is positively influenced by the health and functioning of children with pediatric impairments, and mothers' well-being is positively influenced by the health and functioning of children with pediatric disabilities [29]. As a result, counseling should include not only the children but also the mothers who are caring for them.

The results showed that the mean psychological burden of respondents was 78.14, and the QoL of CP children was 43.14. A significant inverse correlation was found between psychological burden and CP children's QoL (r=-0.142; P=0.012). The study adds knowledge regarding health education for all segments of society towards parents' burden. Further study is needed to explore the needs of parents of CP children.

Study limitations

Parents' estimates of their children's QoL are often close to their CP children's self-report. However, disparities certainly exist, particularly in the psychological dimensions, and it is essential to incorporate the child's perspective whenever possible.

Study suggestions

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

One of the key objectives for minimizing the burden on mothers of impaired children is to design therapeutic programs to lessen the psychological burden on parents of children with cerebral palsy.

A manual booklet on how to cope with CP children should be written in simple language and illustrated with appealing images, and distributed to the parents. More research is needed to assess the requirements and concerns of families with CP children.

5. Conclusion

Mothers expressed a high level of psychological burden as a risk for psychiatric morbidity because cerebral palsy is an additional burden factor for the family, and psychological burden mainly arises during acute events. The chronicity of the condition predisposes these mothers to psychological depression. Because of the burden of care, which leads to a relative reduction or induction of parents' demands, mothers' psychosocial burdens are highly connected with their children's QoL.

Ethical Considerations

Compliance with ethical guidelines

The Babylon Health Directorate approved all experimental protocols, and all experiments followed the proper procedures.

Funding

This research did not receive any grant from funding agencies in the public, commercial, or non-profit sectors.

Authors' contributions

All authors equally contributed to preparing this article.

Conflict of interest

The authors declared no conflict of interest.

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