

## Psychological Burdens on Parents of Children with Cerebral Palsy at Rehabilitation Centers in Baghdad City

### الأعباء النفسية على آباء الأطفال المصابين بالشلل الدماغي في مراكز التأهيل في مدينة بغداد

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#### الخلاصة

**الهدف:** تقييم مستوى أعباء الأبوين النفسية المتعلقة برعاية الطفل المصاب بالشلل الدماغي وعلاقته مع بعض الخصائص الاجتماعية والديموغرافية. **المنهجية:** تم اختيار عينة (غرضية) غير عشوائية تتكون من 100 شخص مختارة من أسر الأطفال الذين لديهم شلل دماغي والذين يأخذون العلاج من مراكز التأهيل في مدينة بغداد. البيانات التي تم جمعها من 16 شباط 2016 - 2 نيسان 2016. وجمعت العينة بطريقة المقابلة بواسطة الاستبيان. تم تحليل البيانات باستخدام المقاييس الإحصائية الوصفية والمقاييس الإحصائية الإستنتاجية. **النتائج:** نتائج الدراسة كشفت أن غالبية مقدمي الرعاية كانت الأمهات، وإن معظم العينة أعمارهم (20-39) سنة، لديهم مستوى منخفض من التعليم، وأنهم يعانون من عدم كفاية الدخل، كانت جميع الأمهات ربات بيوت و (30%) منهم ذات مستوى متوسط من الأعباء النفسية. **الاستنتاج:** مستوى الأعباء النفسية تؤثر على الذي يقوم بإعطاء الرعاية للطفل بعلاقة هامة وخصوصا الذين لديهم دخل غير كافي والأمهات ربات البيوت، أظهرت النتائج لا توجد علاقة هامة بين "الخصائص الديموغرافية (عمر الطفل، مدة المرض ومستوى الإعاقة، عمر مقدمي الرعاية، الحالة الاجتماعية، المستوى التعليمي) مع مستوى العبء النفسي لمقدمي الرعاية. **التوصيات:** أوصت الدراسة أن مراكز إعادة التأهيل يجب أن توفر فرصا كافية لمقدمي الرعاية لإجراء مقابلات المتابعة المتكررة التي تقدم المعلومات ليس فقط على الإعاقة للأطفال ولكن أيضا الدعم النفسي للأبوين. وأوصت بأجراء البحوث المستقبلية المتضمنة التدخل النفسي والاجتماعي للحد من عبء أسر الأطفال المصابين بالشلل الدماغي.

#### Abstract

**Objective:** To assess the level of psychological parent burdens related to caring child with cerebral palsy. Identify the relationship between psychological burdens with some socio-demographic data.

**Methodology:** non- probability (purposive) sample of 100 cases selected from the families of children who have cerebral palsy and who are taking treatment from the rehabilitation centers in Baghdad City. The data collect from 16<sup>th</sup> February 2016 – 2<sup>th</sup> April 2016. A structured interviewing was conducted to collected information from parent by questionnaire was developed based on the study objectives such development was employed through review of literature and related studies and some international scales include: Caregiver Burden Scale by (Elmståhl et al, 1996), Caregiver Burden Inventory by (Caserta, Lund & Wright, 1996), Zaria Burden Interview by (Boon Khan Sang et al, 2010), and the Multi-dimensional Caregiver Strain Index by ((MCSI) by (Stull, 1996). The data analyzed by using descriptive statistical measures and inferential statistical measures.

**Results:** The finding of the study have revealed that the majority of caregivers were mothers, most of the sample their age (20-39), most of the parent's lives together, they have low level of education, and they suffer from in inadequate income, all the mothers were house wife, while most father were self –employee and (30%) of them having moderate level of psychological burdens.

**Conclusion:** Significant association between caregiver (father and mother), occupation of parent & monthly income of family with psychological burden. There are no relationships between level of psychological burden of parents and age of child, duration of illness, level of disability, age of parent, marital status, and level of education, family size and number of children inflicted with same disease.

**Recommendations:** The study has recommended that rehabilitation centers should provide sufficient opportunities for repeated follow-up interviews which offer not only information on the children's disabilities but also psychological support for the parents; future research recommended Psycho-Social Intervention Programmed to reduce the parentsburden of children with cerebral palsy.

**Keywords:** Psychological; parents burdens; rehabilitation centers.

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## INTRODUCTION

Among the large variety of childhood developmental disabilities, cerebral palsy (CP) is considered to be the major physical disability affecting the functional development of children<sup>(1)</sup>. Cerebral palsy is the most common cause of disability, with a prevalence of 2 to 3 cases per 1000 live births. It is a serious disorder that has a greater impact on the life of the person affected, on the family dynamics, on society, and on public policies, as it represents a chronic and complex condition that generates high costs<sup>(2,3)</sup>.

When a handicapped child is born, the parent's distress is a severe feeling of guilt, shame, despair, and self-pity which can be overwhelming<sup>(4)</sup>. A caregiver with disabled child is under the risk of having depression, anger, and can be under great stress<sup>(5)</sup>.

Caregivers have striking emotional and behavioral changes such as forgetfulness, depression, dependence, lack of motivation, often felt confined, and fatigue from their responsibilities<sup>(6)</sup>.

Family with a disability child has great stress and they are at risk for negative health such as depression<sup>(7)</sup> while care is part of parenting, it can often generate significant burden when the requirements are excessive and long lasting. This excessive responsibility may adversely affect the physical and psychological health of caregivers<sup>(8,9)</sup>.

## OBJECTIVES OF THE STUDY:

1. To assess level of psychological burden of parents related to caring of child with cerebral palsy.
2. To find out the relation between levels of psychological burden for parents and some demographic characteristics of the family and the child.

## METHODOLOGY

A descriptive correlation study (non-probability) used to assess the level of psychological burden for parents related to caring of child with cerebral palsy in rehabilitation centers in Baghdad City.

Data collection was carried out through the period from 16<sup>th</sup> February 2016 – 2<sup>th</sup> April 2016. To achieve the purpose of the study; data collection was started after obtaining permission from the rehabilitation centers' authorities. These centers were: Medical Rehabilitation Center and diseases of the joints, Algadeer Rehabilitation Center for the Disabled in AL-Sadr City, AL-Salam Center rehabilitation for the disabled, Hamza specialist center for disabled rehabilitation and Mustafa Specialist Center. A questionnaire was constructed by the researcher that includes two parts: **Part I. Socio-demographic Data:** which include socio-demographic data for the child such as Gender, Age, Duration of illness which computed by subtracting the (age - age at diagnosis); And also includes Part 1 the parent demographic such as age, marital status, education, occupation, monthly income of family. **Part II. Psychological burden:** to assess the levels of psychological burden of parents with cerebral palsy children; this part formulation was based on the related previous studies scales which are: Caregiver Burden Scale, Caregiver Burden Inventory, Zaria Burden Interview and the Multidimensional Caregiver Strain Index; this domain is measured through (15) items. The Validity of the questionnaire has been determined through (15) a panel of experts; Reliability of the Questionnaire was developed by Alpha correlation coefficient, It was 0.89. Interview was conducted to collect information from parents; the interview has been taken

place at the room where the caregiver stayed with child during physiotherapy. CP was diagnosed by specialist before collecting data the objective of the research was explained to the participants to obtain their agreement to participate in it. Data are analyzed through using the Statistical Package of Social Sciences (SPSS, Version 16) performed through the use of descriptive statistical data analysis approach; such as frequencies, percentages, and inferential statistical data analysis approach; such as Chi-Square test.

## RESULTS:

**Table (1): Demographic characteristics of Cerebral palsy child**

Variables		F	(%)
<b>Gender</b>	Female	44	44.0
	male	56	56.0
	Total	100	100.0
<b>Age</b>	1-3	59	59.0
	4-6	30	30.0
	7-9	9	9.0
	≥10	2	2.0
	Total	100	100.0
<b>Duration of illness</b>	<1	19	19.0
	1-3	52	52.0
	4-6	20	20.0
	7-9	9	9.0
	Total	100	100.0

Table (1) shows distribution of demographic characteristics of CP child. It refers that (56 %) of CP children were male, (59 %) of them were in the age group (1-3), & (52%) their duration of illness between (1-3) years.

**Table (2): Demographic characteristics of the parents**

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Variables		F	(%)	
Caregivers	father	33	33.0	
	Mother	67	67.0	
	Total	100	100.0	
Age	20-29	43	43.0	
	30-39	41	41.0	
	40-49	16	16.0	
	Total	100	100.0	
Marital status	Married	96	96.0	
	Widowed	4	4.0	
	Total	100	100.0	
Educational level	Illiterate	10	10.0	
	primary	45	45.0	
	secondary	31	31.0	
	institute and more	14	14.0	
	Total	100	100.0	
Occupation	Father	Employee	12	12.0
		Self-employed	21	21.0
		Housewife	67	67.0
		Total	100	100.0
	Mother			
		Total	100	100.0

Monthly income	sufficient	23	23.0
	some have sufficient	36	36.0
	insufficient	41	41.0
		100	100.0

Table (2) It appeared that the majority of caregiver were mother (67 %), (43%) of them were in age group of (20-29). According to marital status majority of the sample (96 %) were married, (4%) of them were widowed; in regard to their educational level the table indicate that the highest levels (45%) were primary school graduate. According to occupation all the mother (67 %) of the sample was housewife while (21 %) were self-Employed for father. About monthly income for the family (41%) their income is insufficient and (36%) were some have sufficient.

**Table (3): Level of psychological burden**

	level	f	(%)	Mean & stander deviation
<b>Psychological Burden</b>	Mild	24	24.0	
	Moderate	30	30.0	
	Severe	26	26.0	29.83
	very severe	20	20.0	6.702
	<b>Total</b>	100	100.0	

Table (3) shows distribution level of psychological burden. It shows that the highest percentages (30%) of parent has moderate psychological burden while (20%) of them have very sever level of psychological burden.

**Table (4) :Distribution in the Levels of Psychological burden Regarding the Demographic Characteristics**

Levels of Psychological burden											
Demographic		Mild		Moderate		Severe		Very severe		Total	
		F	%	F	%	F	%	F	%	F	%
Caregiver	Father	13	13.0	12	12.0	7	7.0	1	1.0	33	33.0
	Mother	11	11.0	18	18.0	19	19.0	19	19.0	67	67.0
	Total	24	24.0	30	30.0	26	26.0	20	20.0	100	100.0
Age	20-29	9	9.0	13	13.0	9	9.0	12	12.0	43	43.0
	30-39	7	7.0	13	13.0	13	13.0	8	8.0	41	41.0
	40-49	8	8.0	4	4.0	4	4.0	0	0.0	16	16.0
	Total	24	24.0	30	30.0	26	26.0	20	20.0	100	100.0
Marital status	Married	24	24.0	30	30.0	24	24.0	18	18.0	96	96.0
	Widowed	0	0.0	0	0.0	2	2.0	2	2.0	4	4.0
	Total	24	24.0	30	30.0	26	26.0	20	20.0	100	100.0
Level of education	Illiterate	2	2.0	2	2.0	1	1.0	5	5.0	10	10.0
	Primary	8	8.0	13	13.0	15	15.0	9	9.0	45	45.0
	Secondary	8	8.0	10	10.0	7	7.0	6	6.0	31	31.0
	Institute & more	6	6.0	5	5.0	3	3.0	0	0.0	14	14.0
	Total	24	24.0	30	30.0	26	26.0	20	20.0	100	100.0
Occupation	Employee	5	5.0	5	5.0	2	2.0	0	0.0	12	12.0
	Self-employee	8	8.0	7	7.0	5	5.0	1	1.0	21	21.0
	House wife	11	11.0	18	18.0	19	19.0	19	19.0	67	67.0
	Total	24	24.0	30	30.0	26	26.0	20	20.0	100	100.0
Monthly	Sufficient	12	12.0	6	6.0	3	3.0	2	2.0	23	23.0

Some	have	8	8.0	13	13.0	8	8.0	7	7.0	36	36.0
	Sufficient										
	Insufficient	4	4.0	11	11.0	15	15.0	11	11.0	41	41.0
	Total	24	24.0	30	30.0	26	26.0	20	20.0	100	100.0

The table (4) shows that (19%) of the sample are mothers with severe and very severe levels of psychological burden; while (13%) were fathers having mild levels of psychological burden; (11%) are mothers having mild levels of psychological burden; while (1%) are fathers having very severe levels of psychological burden. The table also shows that most of the study sample (13%) having moderate levels of psychological burden, are from age (20-29) and (30-39); (13%) having severe levels of psychological burden, from age (30-39); (4%) of sample have severe levels of psychological burden, from age group (40-49) and (4%) having moderate levels of psychological burden. Regarding the marital status, (30%) having moderate levels of psychological burden are from (married); while (2%) of the sample have severe levels of psychological burden are (widowed) and (2%) of them also having very severe levels of psychological burden. Concerning the level of education, (15%) of the sample having severe levels of psychological burden are group (primary) school graduate; (1%) also have severe levels of psychological burden are group (illiterate). (19%) of the sample have severe levels of psychological burden are occupation group (house wife) and (19%) of them also having very severe levels of psychological burden; (1%) having very severe levels of psychological burden are occupation group (self-employee). Regarding monthly income, (15%) having severe levels of psychological burden are with (insufficient) income ;(2%) of the sample having very severe levels of psychological burden is with (sufficient) income.

**Table (5): Association between psychological burden and Demographic variables and Level of disability**

Demographic Characteristics	No	psychological burden	
		X <sup>2</sup>	sig
Age of child	100	9.355	0.405
Duration of illness		10.114	0.341
parents		13.054	0.005
Age of parents		11.163	0.083
Marital status		5.048	0.168
Level of education		12.940	.165
occupation		13.508	0.036
Monthly income		17.704	0.007
Level of disability		11.003	.5290
X <sup>2</sup> =chi square ,sig= significant, No= number, At the level of P-Value < 0.05			

This table shows that there is: significant association between (father and mother) (p= 0.005), occupation of caregiver (p< 0.036) & monthly income of family (p<0.007) with psychological burden.

## DISCUSSION

Table (1) shows that more than half of the CP children were males while (44%) are female this result revealed that prevalence of cerebral palsy in male more than female. This result was agreed with Danby, et al (2015) who found that 54% were male and 46% were female <sup>(10)</sup>, also Mason, et al, (2015) who concluded that (74%) male and (26%) female <sup>(11)</sup> and more than half are in age group (1-3). During this stage, children learn to walk, talk, solve problems, relate to others

and learn to be independent. Danby, et al (2015) also in their study who found that mean age of the children with cerebral palsy was (26 months)<sup>(10)</sup>. Mudale, et al, (2008) this result were against our results who found that (50%) of CP at preschool age<sup>(12)</sup>. The duration of illness recorded that more than half (52%) their duration of illness between (1-3) years. Nimbalkar & Raithathac (2014) who mention that mean duration of illness in years (3.07)<sup>(13)</sup>. Table (2) shows that the results of the presented study reflected that majority of caregivers (67%) are mothers of the children. The mother is first one responsible for caring and household all the family members while the father spend most of their time in work. This is consistent with a study by Maroon et al, (2013) who mention that (88.7%) of his compel were women<sup>(14)</sup>. Wijesinghe, et al, (2013) also in their study revealed that (97%) of the principle caregivers of the children with cap were their mother<sup>(15)</sup>. Regarding the age (84%) of caregiver's age is between (20 -39 years). this may be because this age is the acceptable in our society for women to get married and it is considered the most productive age to have child. This result agreed with a study by Wijesinghe, et al, (2013) who stated that most common age of caregivers are (20-39).<sup>(15)</sup> Nimbalkar & Raithatha (2014) their study found that mean age in years (35.85)<sup>(13)</sup> Mudale et al (2008) concluded that (68%) of caregiver's age is between (25 to 38 years)<sup>(12)</sup>. Kumara & Venus (2014) who found that most of the caregivers (88.6%) were mothers of the children with cerebral palsy they were in the age group of 21-40 years<sup>(16)</sup>. According to marital status majority of the sample (96 %) were married, (4%) of them were widowed. The marriage means to sustain life, and the reconstruction of the ground for cooperation, the wife of her husband enough housekeeping things, and the creation of livelihoods, and the pair gain enough burdens, and the management of the affairs of life. These findings coincide with the finding of Maroon et al, (2013) who found that (90.3) of caregivers are married, separate (6.5) and widow (1.6)<sup>(14)</sup> In regard to their educational level the table (2) indicates that the highest levels (45%) were primary school Graduate. This finding present evidence that the nature of our society beliefs about female education, the family do not allow them to join schools and make them married. This results disagreement with studies of Wijesinghe, et al, (2013) who stated that (60%) of the caregivers had completed post -primary education<sup>(15)</sup>. Kumara & Venus (2014) findings on education level shows more than half (53.3%) of the parents completed their secondary school.<sup>(16)</sup> that against our findings. Mudale, et al, (2008) their study concluded that more than half (60%) of caregivers were illiterates.<sup>(12)</sup> This result reflected that most of caregivers are not working and their level of education is low. According to occupation all the mother (67 %) of the sample was housewife. this is related to the nature Iraqi society that encourages female to stay at home and takes care for children. This result agreed with a study by Mason, et al, (2015);&Ribera et al, (2014) who reported that most common occupations for mother are work in the home and give care to their children<sup>(11,17)</sup>. About monthly income for the family (41%) their income is insufficient. Ogunlesi et al, (2008) mention that CP is more prevalent in people of lower socioeconomic status<sup>(18)</sup> who agrees with Kumara & Venus (2014) who indicated that socioeconomic factor also appears to be important families from low SES group have lack of knowledge which leads to poor skills<sup>(16)</sup>.

Table (3) this result shows that caregivers are more likely to have wide range of Psychological Burden. This result is supported by Mudale, et al, who found that caregivers with CP suffering from a huge psychological burden with (94%) of them feeling frustration that lead to develop the untruth, isolation and broken heart<sup>(12)</sup>. Wijesinghe, et al, (2013) who concludes that caregivers of children with CP show a high prevalence of psychological problems; There are a number of factors predictive of caregiver psychological problems, particularly the level of caregiver burden, which need to be considered when developing long term care plans for children with CP<sup>(15)</sup> Nimbalkar & Raithatha (2014) who reported that parents with cerebral palsy



experienced a wide variety of negative emotions which ranged from mild anger to tiredness and frustration<sup>(13)</sup>. Danby et al, ( 2015) Their findings corroborate the sentiments as most caregivers complained of psychosocial problems as measured by the Caregiver Strain Index and reported anxiety or depression on the Europol 5 dimensions questionnaire (EQ-5D). Participants in the study were more likely to report anxiety and/or depression compared to the general population. It therefore seems reasonable to attribute the increased anxiety or depression to be secondary to the burden of care giving<sup>(10)</sup>.

Table (4) This result reflects that mother more than father with psychological burden this may be because that mother first one responsibility for caring of the child. this result supported by Byrne, et al, (2010) who conducted a quantitative study with 100 mothers and 61 Fathers of children with CP and observed that mothers spent more time caring for the Child than fathers and those mothers had worse mental and physical health<sup>(19)</sup> Camargo's et al, (2009) in their study mentions psychological health of primary caregivers, normally the mothers is strongly related to the behavior and time demand that the child requires. In many cases, the caregivers change the dynamics of their lives and stop performing their social Roles due to the child with CP. Thus, the responsibilities that this function promotes lead to the tiredness, isolation, and stress on the part of the caregivers.<sup>(20)</sup> Regarding age, this result supported by Cain and Wicks (2000) who stated that younger caregivers experiencing higher stress as they gained higher burden scores because they manage more commitments such as career, family and work compared to the caregivers age more than 65 years old.<sup>(21)</sup>

Also Wijesinghe, et al. (2013) that concluded, the majority of the sample (81, 3 %) age between (20-39) years shows a high prevalence of psychological problems among Caregivers of children with CP. There are a number of factors predictive of caregiver psychological problems, particularly the level of caregiver burden, which need to be considered when developing long term care plans for children with CP.<sup>(15)</sup> Rania et al, (2004) who mention that social support had indirect effects on psychological and physical health through family functioning<sup>(22)</sup>. Tania et al (2002) who found that if the marital relationship is good then spouse can help each other by giving support and understanding to each other<sup>(23)</sup>. Concerning the level of education, this result supported by Wijesinghe, et al, (2013) who concluded that the caregivers who are more likely to suffer from psychological burden were those having a high level of caregiver burden and low educational status<sup>(15)</sup>. Mudale, et al, (2008) Who mention that caregivers are likely to have lower educational attainment, have diminished opportunities of finding employment and subsequently are at high risk of financial strain<sup>(12)</sup> About occupation for caregiver this result supported Mudale, et al, (2008); kumara & Venus (2014) who concluded unemployed caregivers are likely to report financial burden and this may contribute towards distress or depression.

Table (5) this table shows that there is: significant association between caregiver  $p < (0.005)$  with psychological burden. Do not found supporting study for this result. Significant association between occupation of caregiver  $p < (0.036)$  with psychological burden. This result supported by Danby, et al, (2015) who found that there is association significance between psychological burden and unemployment group.<sup>(10)</sup> There is significant association between monthly income  $p < (0.007)$  with psychological burden. This result disagreement with Wijesinghe, et al, (2013) shows that occupation & income not a significant association with caregiver psychological burden.<sup>(15)</sup>

## CONCLUSION

The majority of caregivers were mothers, the study concluded that all caregivers of cerebral palsy child are impacted by psychological burden in differences levels, the caregiver who are age

(20-29) years are impacted with level of psychological burden more than other. The caregivers who have low level of education (primary school graduates) suffer more from psychological burden, housewives caregivers are impacted with psychological burden more than other.

### RECOMMENDATION:

According to result of the study, the following recommendations have been made:

1. Rehabilitation centers should provide sufficient opportunities for repeated follow-up interviews which offer not only information on the children's disabilities but also psychological support for the caregivers.
2. Future research recommended Psycho-Social Intervention Programmed to reduce the family burden of cerebral palsy child.

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