Psychological Burden of a Child with Cerebral Palsy Upon Caregiver in Erbil Governorate.

Eqbal A.Mu'ala , Abas Al. Rabati, Shukir S. Shwani

ABSTRACT:

BACKGROUND:

A with disabled child have a great burden on caregiver is, they are under the risk of having depression, anger, and can be under great stress. Caregivers have stroking emotional and behavioural changes such as forgetfulness, depression, dependence, lack of motivation, often felt confined, and fatigue from their responsibilities.

OBJECTIVES:

To assess the psychological burden of child with Cerebral Palsy (CP) upon his/ her caregivers.

METHODOLOGY:

A descriptive study was conducted in the Helena Center (HC) in Erbil Governorate for handicapped children from 15th February to 15th March 2005; Data were analyzed by using frequencies, percentages, mean of scores, comparative significant, Pearson's correlation, and multi regression analysis.

RESULTS:

Of the study indicate that (85%) of caregivers are child's mothers (68%) their age between (25–38) years, (60%) are illiterate, (79%) come from low Socio Economic Status (SES), (46%) live in crowded situations, (50%) of CP at preschool age, (54%) were males, (58%) of CP children diagnosed at infant stage. (80%) of CP is spastic type, (34.4%) of CP children have mutism, and (33.7%) has Mental Retardation (MR) accompanying CP.

CONCLUSION:

There is a highly significant association between the psychological burden and the age of caregiver, crowding index, complications like mutism, MR and epilepsy.

KEYWORDS: cerebral palsy, caregivers, psychological burden.

INTRODUCTION:

The term CP came into use in the late 1860's. Sir William Little, a British medical doctor (1).

(2) defined CP as a term used to describe a group of disorders affecting body movement and muscle coordination (3). 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 (4). A caregiver with disabled child is under the risk of having depression, anger, and can be under great stress (5). mothers of children with CP may be at risk of depression, and the interventions that take into account the moderating effects of social support may increase maternal adaptation(6). caregivers have stroking emotional and behavioural changes such as forgetfulness, depression, dependence, lack of motivation, often felt confined ,and fatigue from their responsibilities(7). It has been reported that the family, who has a handicapped child born into it and who grows into adulthood, is one of the most stressful experiences a family can endure.

Parental reaction to the realization that their child is exceptional usually includes shock, anxiety, guilt, sadness, and depression (8). 50% of patients with CP have mild disability, 10% are severely handicapped, 25% have average intelligence; 30% are mentally retarded; about 35% of those with the syndrome suffer from seizures and 50% have speech disorders (9). About 10% or more of individuals under the age of 17 years have a chronic illness or disability. These youths may have survived life threatening illness which until recently caused a high mortality rate, or survive longer although they suffer from fatal illness (8). more than half of all women will provide care for an ill or disabled person at some point in their life (10). Parenting high risk infants presents additional challenges and stress to families struggling to cope with raising children. Parents of high risk infants have higher anxiety levels and depression which is more common (11). Family with a disability child has great stress and they are at risk for negative health such as depression (12).

---

* College of Nursing, Baghdad University.

** College of Medicine, Hawler Medical University Erbil Kurdistan Region.

***College of Nursing, Hawler Medical University Erbil Kurdistan Region.

AIM THE STUDY:

1- Identify the psychological burden of a child with cerebral palsy upon their Caregiver. 2- Identify the relationship between the burden aspects, child, family and some demographic characteristics (age, sex, job, occupation, marital status, SES, age of CP child, type of CP and complications accompany the CP).

Methodology: A descriptive study is conducted. Data were collected for the period of February 15th to the 15th of March, 2005 in order to identify the burden of child with CP upon his/her caregiver in Erbil Governorate. The study was carried out in Helen Canter (HC) for handicapped children.

A non–probability (purposive) sample of (100) caregivers who provide care for their children with CP and who were weekly or monthly visit HC for physiotherapy were selected.Data was collected by using questionnaire format and filled out by caregivers of children with CP who were interviewed by the researcher, and who accepted to participate in the study. Each interview session took approximately (30– 45) minutes.

Analyzing data with the:-

I. Basic descriptive statistics.

II.Pearson'scorrelation

RESULTS:

Table (1) :Demographic characteristics of CP child's caregiver

Variables	Number	%
Person responsible		
• Mother	85	85
• Both parents	9	9
• Sister	4	4
• Aunt	2	2
Total	100	100
Age		
• 18- 24	6	6
• 25 -31	35	35
• 32 – 38	33	33
• 39 – 45	18	18
• Above 45	8	8
Total	100	100
Mean = 28.70 SD = 1.041		
Level of education		
• Illiterate	60	60
• Able to read and write	20	20
• Primary school Graduate	6	6
• Intermediate school Graduate	8	8
• Secondary school Graduate	4	4
• Institute and University Graduate	2	2
Total	100	100
Socioeconomic status *		
• High SES 80 - 100	3	3
• Middle SES 60 - 79	18	18
• Low SES 0 – 59	79	79
Total	100	100
Crowding index * (27)		
High 1-1.9	13	13
Intermediate 2-2.9	20	20
3- 3.9	21	21
Low 4 +	46	46
Total	100	100

Table (1) shows that the first person's responsible to child's care was the mother. It represents 85%, the age of caregiver ranged between (25 – 31) years and represents 35% and 33% age (32-38) years. The illiterate caregiver recorded high percentage 60% and 20% can read and write, while the rest is above primary school , (79%) of caregivers came from low socioeconomic families, and (46%) came from crowded houses.

Table (2): Demographic characteristics of CP child

Variables	Number	%
developmental stage		
- Toddler	30	30
- Preschool age	50	50
- School age	20	20
Total	100	100
Sex		
- Male	54	54
- Female	46	46
Total	100	100
Developmental stage at diagnosis		
- Newborn	39	39
- Infant	58	58
- Toddler	3	3
Total	100	100

Table (2) shows that 50% of CP children in preschool age, 54% were males, 58% were infants at diagnosis while newborns represent 39%.

Table (3): Types of CP and its complications.

Variables	Number	%
Type of CP		
- Spastic	80	80
- Dyskinitic	10	10
- Ataxic	8	8
- Mixed	2	2
Total	100	100
Complications		
- Mutism	96	34.40
- Deafness	22	7.90
- Mental retardation (MR)	94	33.70
- Epilepsy	49	17.56
- Blindness	18	6.44
Total	279 *	100

*There are more than two complications found with CP child, therefore the frequency of complications are 279. Table (3) shows that the Spastic CP represented 80%, 34.4% of children with CP have mutism , and 33.7% of them have MR .

Table (4): 3-level scale by total frequencies, percentages, mean of score and comparative significance of psychological burden

I.D	Scales / Psychological Burden items	Always F	%	Sometimes F	%	Never F	%	Mean of Scores	C.S
	Because of my handicapped child								
1	I have been frustrated since his birth.	94	94	5	5	1	1	2.93	H.S
2	I have been saddened because of mutism.	95	95	-	-	5	5	2.90	H.S
3	I have depression because of epilepsy	60	60	2	2	38	38	2.22	S
4	I have stress because of the child's gait.	100	100	-	-	-	--	3	H.S
5	I have stress because CP is uncured.	97	97	3	3	-	-	2.97	H.S
6	I have stress because of no future.	94	94	6	6	-	-	2.94	H.S
7	I feel guilty.	90	90	2	2	8	8	2.82	H.S
8	I cry.	84	84	15	15	1	1	2.83	H.S
9	I have disturbance of sleep	74	74	26	26	-	-	2.74	H.S
10	I lost my appetite	65	65	31	31	4	4	2.61	H.S
11	I Lost interest in life	87	87	10	10	3	3	2.84	H.S

F : Frequency
CS: Comparative significant S : significant HS : highly significant

This table shows that all the (11) items were highly and significantly affected caregivers psychological status except item (3) which

Table (5) :Association between demographic characteristics and caregiver's psychological burden

predictors	Psychology burden		
	β	t	ρ
age of caregiver	0.57	2.302	.0235
Mutism	0.81	2.959	.0039
MR	0.49	4.786	.0000
Epilepsy	0.52	4.464	.0000
crowding index	-0.070	-2.401	.0001
R2 .325	R= 30.41	F = 15.43	ρ = .0000

There is a highly significant association between the psychological burden and age of caregiver, crowding index and complications like mutism and MR.

DISCUSSION:

(Table1). The results of the presented study reflected that majority of caregivers (85%) are mothers of the children. this is consistent with a study by 90% of children caregivers were their mothers(4).. Regarding the age 2/3 (68%) of caregiver's age is between (25 to 38 years), this is the child bearing age. More than half (60%) of caregivers were illiterates. This result reflected that most of caregivers are not working and their level of education is low. This result agreed with a study by (Fielding,And Duff) whom stated that the educational variable of mothers has certain effect in the pattern of child care(14). Low Socioeconomic Status (SES) considers one factor which affected mother's nurtures of the child.. The family income of the present study shows that (79%) of them do not have sufficient income which agrees with Peter who study indicated that socioeconomic factor also appear to be important. Families from low SES group have lack of knowledge which leads to poor skills (13). Also the table shows most of them live in crowded houses which represents (46%) with more than four people in one room.

Table (2) shows that half of the CP children are in preschool age, and more than half are males while (46%) are females. This result agreed with Fielding, D. And Duff, A who stated that males - females ratio was 1.3:1 (56% male and 44% female) (14). The age at diagnosis recorded that more than half (58%) were infants at the time of diagnosis. Schwartz,M. W .; Bell, L.M. Bingham,P.J.; chung, E.K.; Cohen, M.I .;Friedman, D. and Mulbeg, a .E .:in their study mentioned that infants during the first 6 months may be diagnosed especially when the family expresses concerns that their child's milestones are delayed more than usual. (15).

Table (3) shows that the spastic CP recorded 80% of the study sample. This result is consistent with phenomenological study of the experience of being a mother of a child with cerebral palsy; the spastic CP recorded high percentages(16). Study of the CP child by Palfi , I ; Blassuzaur , B . : stated that the spastic represent (70-80%), athetoid or dyskinitic is (4-8%), ataxic is (5-10%) and mixed is (1-2%)(19); this result consist with the present study. Mutism is one of the complications and represented (34%). While MR is (33%) this result agrees with study performed in Italy the complications with CP child. He reported that (30%) has mental retardation, (10%) severely handicapped, (35%) has epilepsy and other complication is (25%)(9). Mental retardation is one of the most frequently encountered and most distressing disability among children in industrialized and developed countries (18). Table 4 shows that caregivers suffering from a huge psychological burden with (94%) of them feeling frustration that lead to develop the untruth, isolation and broken heart. This result agrees with a study reported that stress appears daily while caregivers try to maintain their work; then frustration and conflicts also appears (19). caregivers' having a handicapped child born into a family and who grows into adulthood is one of the most stressful experiences a family can endure. Parental reactions to the realization that their child is exceptional usually include shock, depression, guilt, sadness, and anxiety (17). Epilepsy is another complication suffered with CP child.

All the care-givers who having child with CP and epilepsy who they are complaining for depression, (60%) of caregivers having depression because of child epilepsy. A descriptive study conducted in Canada with children who have CP with epilepsy and other complications such as vision impairment and mutism. The study shows children of families with complications are at high risk for poor psychosocial outcomes, social isolation, family conflict, depression caregiver, frustration, helplessness, anger and fear(18) . Grady .P.A.; Armistrong .N. and Helmers.K Stated that the CP remains uncured while the caregivers have wished it have been too cured. Therefore (97%) of caregivers in the study feels stress because the conditions of the child remain unchanged (12). Wood (2004) mentioned that CP isn't curable; however getting the right therapy for the child can make a difference in reducing the long-term impact of the condition upon caregivers (3).

The future of a child also is another hope of parents but when they see his/her sibling with no future the depression and stress increase; (94%) of caregiver in present study say I have stress because of no future.There are emotional and behavioral changes such as forgetfulness, depression, dependence, and lack of motivations. Caregivers often feel confined, overwhelmed, and fatigued due to their responsibilities, but they are reluctant to give up or share their caregiver role (20). The majority (90%) of caregivers feel guilty because of the heavy burden of the child's disability; this results, consistent with Kasuya, R.T.: polgar,B, P. and Takeuchi, R who stated that parents of handicapped children feel guilty and worthless, obsessions(21). states that the mother and father often feel guilty and wonder what they did to cause their child to have a disorder(22) .

The cry is one of the inadequate expressions of the psychological burden of a caregiver with a disabled child, when she doesn't get a response to her questions, she starts crying. The result of the study shows that (84%) of caregivers cry when the child's problem is not solved. This result agrees with Smith , ,P. M) when he studied the parenting of a child with special needs in the USA. He saw that guilty feelings may also be manifested in spiritual and religious interpretation of blame and punishment. When they cry, why me? Why my child? Many parents are also saying, 'why has God done this to me? (23). An increase in somatic complaints, such as indigestion, changes in appetite, and headache, often accompanies caregiver's burden.

Other common signs include fatigue, weight loss or gain (21). For sure, caregivers have psychological disorder; the study shows that (74%) of caregivers have sleeping disturbance, (65%) of them lose appetite. This result is consistent with a study indicated that the signs and symptoms of depression are loss of interest, loss of pleasure, sleep change, weight loss, and loss of appetite(24) .

CONCLUSION:

The majority of caregivers were children's mothers, their average age is between 25-38 years old, and 60% are illiterate. Two third of caregivers come from low socioeconomic status. A highly significant association is recorded between the complication associated with the CP child such as mutism, MR, deafness, epilepsy, and blindness, with psychological burden.

RECOMMENDATIONS:

1. Early diagnosis will help the poor family to prevent CP complications.
2. Prenatal, perinatal and postnatal care is very important to prevent the occurrence of CP.
3. Neonatal screening test to detect preventable causes of cerebral palsy.
4. Counselor helps parents learn how to modify behavior and assists physiotherapist to rehabilitate the CP child.
5. The Medicare and Medicaid program should be developed for caregivers.
6. Established Cerebral Palsy Association helps the Government and Ministry of Health identify the barriers located on caregivers.

REFERENCES:

1. National Institute of Neurological Disorders and Stroke (NINDS): Cerebral palsy : Hope through research united cerebral palsy association. Inc,Washington , D.C.,USA, 2005, 3.
2. Canada Cerebral Palsy Association .: Cerebral Palsy question and answer , promoting enhancing on environment where individual with cerebral palsy are able to maximize their potential and improves their lives.; the Canada Cerebral Palsy Association 2005, 1-17.
3. Wood, D.: Cerebral Palsy Disease, condition and injuries. National Institute of Neurological Disorders and Strokes (NINDS) , 2004, 1-6 .
4. Wheless, J.W.: Mental handicap and Cerebral Palsy, Epilepsy. Com, 2004, 1 - 10.
5. Simpson, J.: Parenting a child with cerebral palsy (or parents rights). UCP National , Washington DC ,2004 , 1-5.
6. Raina ,p.; o'Donnell,m; Heidi . Schwellnus,h; Rosenbaum ,p; King ,G; Brehant, J;Russell, D.Swinton,M.; King, Susanne,K;Micheline ,W; Walter, S.D; and Wood, : Caregiving process and caregiver burden : Conceptual models to guide research and practice . BMC pediatric Journal Jan 2004; 4 , 1-2.
7. Grant, J.S. , ;Glandon ,GL . ; Elliott, TR.; Giger , JN.and weaver ,M .: The concerns of family caregivers of stroke survivors over the first month. Medscape Nurses Journal; 2004, 6, pp. 27, 105-111.
8. Cohen, M.A.: Impact of a handicapped child on the family. Yala – New Haven Teachers Institute, 2004, 1-6.
9. Ferrari, F.: General movements in preterm infants predict cerebral palsy, the university of Made in Italy . Archives Pediatric Adolescence Medical Journal 2002; 156, 460- 467,422-423.

10. Meyer , M. H. : Care work gender labor and the welfare state . London , 2000, 203 - 215.
11. Hummel, P . : Parenting the High - Fisk Infant, WB Saunders. National Biodiversity Information Network (NBIN) ; 2003; 3 .88-92.
12. United Cerebral Palsy (UCP).: Parenting and families safety Assisting People with Disabilities in A Disaster .Washington DC, UCP, 2004, 1- 2.
13. Peter ,J.:Prospects for preventing asthma, Archives of disease in childhood Journal ,No(8).1999, 404-405.
14. Fielding, D. And Duff, A.: Compliance with treatment protocols: Intervention for children with chronic illness. Archives of disease in childhood, No (80), 1999, 196-200.
15. Schwartz,M. W .; Bell, L.M. Bingham,P.J.; chung, E.K.; Cohen, M.I .;Friedman, D. and Mulbeg, a .E .: The 5 – minute pediatric consult . 3rd edition, London, Lippincott Williams and Wilking , 2003, 230-231.
16. Wong, D. and Wilson , D . : Wong's; Nursing Care of Infant's and Children. 7th edition, Philadelphia, Mosby , 2003, 503, 1834-1843.
17. Glasscock R, : A phenomenological study of the experience of being a mother of a child with cerebral palsy, Pediatric Nurses Journal 2000 ; 29, 407-10.
18. National Center on Birth Defects and Developmental Disability (NCBDDD).: Economic costs Associated with Mental Retardation, Cerebral Palsy, Hearing Loss, and vision impairment . United States,. Morbidity and Mortality weekly Report (MMWR) ; 2004, 57-9.
19. Palfi , I ; Blassuzaur , B . : Struggling alone : Nurses in Hungary , Bulletin of Medical Ethics Journal , 2002, 14-15.
20. Grady .P.A.; Armistrong .N. and Helmers.K.: Research In Informal Caregiver : state of the science work group meeting. The National Institute of Nursing Research (NINR) session, Bethesda Maryland. 2001, 1-6.
21. Kasuya, R.T.: polgar,B, P. and Takeuchi, R.: Caregiver burden and burnout : A guide for primary care physicians . Postgraduate Medicine Journal ; 2000;108 , 119 – 23.
22. Bacharach.M.: Cerebral Palsy ; AGuide for care, Orthopedic Department , The ALFREDOI Dupont Institute ;Home page. 2004, 1-8.
23. Smith , ,P. M . : Parenting a Child with Special Needs, The national information canter for children word with disabilities (NICHCY), 2002, 320.
24. Shultz . J. and Sheila , J . M . : Psychiatric Nursing care plans, Philadelphia. Lippincott company, 2002 ;164 , 328.