

Parents psychological Burden of Care for Children with Mental Retardation in The Middle Euphrates Governorates

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Abstract : The responsibility of caring for mentally retarded child can contribute to parent's burden. The study shows that parents of children with mental retardation experience high level of burden.

Objective: The present study aims to assess the level of psychological burden of care among parents who have children with mental retardation and to identify the relationship between parents burden of care for children with mental retardation and their sociodemographic data such as age, sex etc. **Methodology:** A descriptive -analytical study design was conducted on 22th January 2016 to 25th march 2016. A purposive (non-probability) sample of (90) parents (mother or father) were selected throughout the use of non- probability sampling approach, that include parents who have children with mental retardation attending mental disability care institute. The questionnaire items were constructed by the researcher for the purpose of present study. In order to test the validity of the questionnaires, the instrument was presented to panel of experts in different fields to make it more valid. Data have been analyzed by using descriptive and inferential statistics.

Results: The results of the study show high psychological burdens due to the handicap children. There is a significant relationship between the levels of parents' burdens and their child hand cap degree and the monthly income. As for the psychological status present a significant differences between the psychological burden and the parents level of education and residency. but there are statistical non significances between the parents burden with other parents demographical data.

Conclusion: The study concluded that there is high level of parents psychological burden due to the presence of mental retardation child in the family. The level of mental retardation is very important indication about the level of the burden.

Recommendations: The study is recommended that future researches should be directed towards exploring psychological intervention factors which help to minimize the burden on parents of children with mental retardation.

Keywords : mental retardation, burden, children.

Introduction

Mental retardation (MR) is a general neurodevelopmental disorder seen as meaningfully reduced intellectual and adaptive effective. It is called intellectual developmental impairment (IDI), general learning impairment, or Intellectual disability (ID) ¹.

It is characterized by a total IQ below 70, in adding to deficits in 2 or more adaptable activities that disturb every day general activities. The description now consists of two factors, one concerning mental operational aspect and the second related to persons' functional skills in their surroundings².

Intellectual disability influences about 3-4% of the overall human population. 76-91% of the afflicted persons have mild mental incapacity. Non-syndromic or idiopathic conditions account for 31-51% of conditions. Nearly a quarter of cases are produced via an anatomical illness³.

Whenever the diagnosis of MR is done, the parents have to make great changes in their desires and expectations for the child. They often experience prolonged depression, guilt, pity or anger, and lack of ability to deal with substantial practical and financial problems. Few of them reject their children, while others become over involved in their health care, sacrificing other important aspects of family life⁴.

Legal responsibility associated with bearing such mentally handicapped children usually influences whole atmosphere of home including regular family life, emotional aspects and financial resources of family. The high level of care needed by a child with mental retardation may become taxing and may even affect both physical and psychological health of caregivers⁵.

With regards to the mothers of children with mental disabilities, they face indifferent behavior and non-cooperation in looking after their children due to not being able to follow up their career and they also experienced marital problems⁶.

It has also been reported that there is an interaction between the child with mental retardation and the family; this interaction may lead to negative dynamics and cause stress and reactions to the child with disabilities⁷.

Also there are other parameters including the socio-economic deprivation of the parents and the pattern the parents care for their children and this may also contribute in elevation of their stress levels⁸.

Objectives of the Study

1. To assess the level of burden of care among parents who have children with mental retardation.
2. To identify the relationship between parents burden of care for children with mental retardation and their sociodemographic data such as age, sex etc.

Methodology

A descriptive -analytical study used the assessment approach to assess the Parents Burden of Care for Children with Mental Retardation in The Middle Euphrates Governorate. This design was carried out in order to achieve the objectives of the present study

A questionnaire was constructed by the researcher.

The questionnaire items based on: Extensive review of related studies and literature.

Scales such as: General health questionnaire, the parental stress scale.

The questionnaire consist of **Psychological burden**: This domain consisted (51 items) it was consisted of (3) subdomains which included:

- a. Anxiety: it consisted of (17) items.
- b. Stress: it consisted of (16) items.
- c. Depression it consisted of (18) items.

In order to test the validity of the questionnaires, the instrument was presented to panel of experts in different fields to make it more valid.

The data collection was carried out from February 24th 2016 to April 3rd 2016. The questionnaire has been administrated personally by the researcher to parents of mental retardation child. Data were analyzed through the application of descriptive statistical analysis (Frequency F., Percentage P.) and inferential data analysis plan (Chi-square) with (SPSS, Version 20).

Results

Table (1) Distribution of the study sample by their Demographic Data

Demographic Data	Rating And Intervals	Mother		Father	
		F	%	F	%
parents age	20-29	3	7.5	2	4
	30-39	15	37.5	11	22
	40-49	16	40	20	40
	50-59	6	15	12	24
	60+	0	0	5	10
	Total	40	100	50	100
parents Levels Of education	Illiterate	8	20	2	4
	Read And Write	6	15	11	22
	Primary School Graduated	11	27.5	20	40
	Secondary School Graduated	7	17.5	12	24
	College Or Institute Graduated	8	20	5	10
	Total	40	100	50	100
parents Occupation	government employee	6	15	13	26
	Private job	2	5	5	10
	free business	1	2.5	18	36
	Retired	1	2.5	13	26
	Unemployed /House wife	30	75	1	2
	total	40	100	50	100

This table shows the study results indicate that the majority of both mother and father are at age group (40-49) years old (40%). In addition, the study results indicate that both mothers and fathers are primary school graduated (27.5%) and (40%) respectively, (75%) of mothers are house wife, (36%) of fathers' occupation is free business.

Table (2) distribution of the study sample by their general information

General information	rating	frequency	percentage	cumulative percent
Social Status Of Parents	Live Together	82	91.1	91.1
	Divorced	3	3.3	94.4
	Separated	5	5.6	100
Who Is Provide Child Care	Mother	82	91.1	91.1
	Father	8	8.9	100
Monthly Income	Sufficient	20	22.2	22.2
	Sufficient To Some Extent	33	36.7	58.9
	Insufficient	37	41.1	100
Residency	Rural	4	4.4	4.4
	Countryside	15	16.7	21.1
	Urban	71	78.9	100
Family Member	1-3	7	7.8	7.8
	4- 6	49	54.4	62.2
	7- 9	27	30	92.2
	10 and more	7	7.8	100
Number Of Handicapped Child	1	74	82.2	82.2
	2	12	13.3	95.6
	3	4	4.4	100

This table shows that (91.1%) of parents are living together, (91.1%) of children are caring by the mothers, (78.9%) of the study subjects are urban residents, (54.4%) of families have 4-6 family members, and (82.2%) of families have one handicapped child.

Table (3) Childs' demographic Data

demographic data	Frequency	Percent	Cumulative Percent
gender			
Male	56	62.2	62.2
Female	34	37.8	100
Child age			
<= 10	23	25.6	25.6
11 - 13	38	42.2	67.8
14+	29	32.2	100
Age at diagnosis			
<= 3	67	74.4	74.4
4 - 7	18	20	94.4
8+	5	5.6	100
Handicap degree			
1	22	24.4	24.4
2	48	53.3	77.8
3	14	15.6	93.3
4	6	6.7	100
Number of brothers			
No brothers	9	10	10
1-3	74	82.2	92.2
4 and more	7	7.8	100
Number of sister			
No sisters	18	20	20
1-3	58	64.4	84.4
4 and more	14	15.6	100
Child series			
1-3	61	67.7	67.7
4 and more	29	32.3	100

This table shows that (53.3%) of the handicapped child are within the moderate degree of handicap, (42.2%) of the children are within the second age group (11-13) years old, (62.2%) of the children are males, (82.2%) of the children have 1-3 brothers, (64.4%) of the children have 1-3 sisters, (67.7%) of the children series is 1-3, and (74.4%) of the children age at diagnosis is 3 years or less.

Table (4) level of psychological burdens

psychological burdens	Levels	Frequency	Percent	Cumulative Percent
psychological burdens	Low	12	13.3	13.3
	Moderate	43	47.8	61.1
	High	35	38.9	100

This table shows that (47.8%) of the parents are exhibit moderate psychological burden, (38.9%) exhibit a high psychological burdens, and (13.3%) exhibit low psychological burden,

Table (5) relationship between parents' burdens/psychological and their demographic data

Demographic data	Rating	psychological			Chi. sq	d.f	p. value
		never be burdens	sometimes burdens	always burdens			
Mother age	20-29	0	1	2	11.693a	6	0.069
	30-39	2	5	8			
	40-49	3	9	4			
	50-59	0	4	2			
Father age	20-29	0	0	2	12.5a	8	0.115
	30-39	1	3	7			
	40-49	4	10	6			
	50-59	1	8	3			
	60+	0	3	2			
Mother level of education	Illiterate	2	4	2	12.625a	8	0.0125
	Able To Read And Write	2	2	2			
	Primary School Graduated	1	6	4			
	Secondary School Graduated	1	4	2			
	College Or Institute Graduated	1	3	4			
father level of education	Illiterate	1	1	1			
	Able To Read And Write	2	2	0			
	Primary School Graduated	1	9	3			
	Secondary School Graduated	3	5	5			
	College Or Institute Graduated	1	7	9			
mother occupation	government employee	1	2	3	3.044a	8	0.932
	Private job	0	1	1			
	free business	0	1	0			
	Retired	0	0	1			
	House wife	5	14	11			
Father occupation	government employee	2	5	6			
	Private job	2	9	7			
	free business	0	1	4			
	Retired	3	8	2			
	unemployed	0	0	1			
Social parents	Live Together	11	40	31	3.796a	4	0.434
	Divorced	1	0	2			
	Separated	0	3	2			
Residency	Rural	1	1	2	5.385a	4	0.025
	Countryside	1	11	3			
	Urban	10	31	30			
Family members	1-3	2	2	3	9.613a	8	0.293
	4-6	5	23	21			
	7-9	3	15	9			
	10-12	1	3	2			
	13+	1	0	0			

This table shows that there is a non-significant relationship between the levels of parents' psychological burdens and their demographic data at p-value more than 0.05. except parent's level of education and residency show significant relationship.

Discussion

The result of the study indicate that 40% of parents are at age group (40-49) years old. This result agree with the findings of (El-Ganzory, et al., 2013) they found that (42%) of the participants' ranged from 40 to more than 50 years old⁹. Also agree with (Ntswane and Rhyn 2007) who found that the majority of both mother and father (50%) are at age group (41-50) years old¹⁰.

According to levels of education the result shows that both mothers and fathers are primary school graduated (27.5%) and (40%) respectively. This result agree with the findings of (Motamedi, et al., 2007) they found that (28%) of mothers are read and write and primary school¹¹. Also the result agree with the findings of (Singh, et al., 2014) they found that (44%) are less than secondary educational level¹².

The result shows that the majority (75%) of mothers is housewives, (36%) of fathers' occupation are free business. This result agrees with the findings of (Kerenhappachu & Sridevi 2014) they found that the mothers of children with mental retardation 93.3% are housewives¹³. This result also agrees with the findings of (Motamedi, et al., 2007) they found that 88% of the mothers are housewives¹¹.

According to the Social Status of parents the result shows that the majority of parents living together (91.1%). This result agree with the findings of (El-Ganzory, et al., 2013) Who found that (50%) were married⁹. This result agree with the findings of (Hussein 2015) who found that More than 50% of both parents in the study reported that no change has happened in their marital life¹⁵.

According to who is provide care the result shows that 91% were mothers while (8.9%) fathers provided child care. These results agree with the findings of (Shanthi, et al., 2015) who found that in their study 83.3% of primary care givers were females¹⁵. This result agrees with the findings of (Hussein 2015) who found that the responsibility of caring for the mentally retarded child is taken by the mothers¹⁴.

According to the monthly income the majority of the parents (41.1%) have insufficient income. This result agree with the findings of (Maheswari 2014) who found that half of the respondents are poor and they do not have other sources of income other than their monthly income to take care of their special children with special needs and borrowed money to meet out the household¹⁶.

According to residency of the parents the result shows that the majority of parents (78.9%) of the study subjects are urban residents. This result agree with the findings of (Kerenhappachu & Sridevi 2014) In the group of mothers of children with mental retardation 93.3% belongs to urban area background¹³. This result agree with the findings of (Chouhan et al., 2016) the mothers of children with mental retardation (63.3%) belongs to urban area background. expenses and treatments¹⁷.

According to number of family members the result shows that (54.4%) of families have 4-6 family members. This result agree with (Parish, et al., 2004) who found that the family members from 3-6 members¹⁸. While this result agrees with the findings of (Lakhani, et al., 2007) who found that the (32%) had 4 members, (35%) had 5 family members¹⁹.

Our result show (82.2%) of families has one handicapped child. This result agree with the finding of (Hussein 2015) who found that maximum of the families (above 86%) had one mentally retarded kids⁽¹⁴⁾.

Our result shows (62.2%) of the children are males. This result agree with the result of (Gupta, et al., 2012) who found that 71.2% of sample are males⁽²⁰⁾. This result agree with the findings of the (Azeem et al., 2014) they found that The sample were 30% females and 70% males²¹.

Our result shows (42.2%) of the children are within the second age group (11-13) years old. This result agree with the result of (Malhotra and Sharma 2013) they found Majority of children belongs to 9-12 years age group (30%)⁽²²⁾. This result agree with the findings of the (Azeem et al., 2014) they found that The mean age of the children was 10.5 years²¹.

Our result show (74.4%) of the children age at diagnosis is 3 years or less. This result agree with the result of (Maheswari2014) he found that majority of their children (56%) have the disability diagnosis from early years after birth¹⁶. These results agree with the findings of the (Azeem et al., 2014) they found that 82% of the children had ID diagnosis since birth²¹.

Our result show (53.3%) of the handicapped child are have moderate degree of handicap. this result agree with the finding of (Lakhani, et al., 2007) who found that (54%) children had mild-to-moderate mental retardation¹⁹. This result agree with the findings of the (Azeem et al., 2014) they found that 42% moderate ID²¹.

The result also shows that (82.2%) of the children have 1-3 sibling.This result agree with (Hakeem and Subathra 2013) they found that (40%) respondents has 3 sibling²³.

The study revealed that psychological burden of parents were(47.8%) moderate burdens, (38.9%) high burden and (13.3%) low burden due to the handicap among their children.This result agree with the findings of (Upadhyaya and Havalappanavar2008) who found parentshave moderate psychological burden(43%)²⁴.

The result shows that no significant relation between age of mother and her burden. This result is supported by the findings of (Jadhav 2013) who found no significant relation between burden and age of the parents or caregivers²⁵.

The result shows that there is no significant relationship betweenage of father and his burden.This results supported by the findings of (Jadhav 2013) who found there was no significant relation was found with burden score and age of the parents or caregivers²⁵.

Concerning the mother level of education result shows that there is a significant relationship between psychological parent's burden and mother level of education at p value (0.0125). This result corroborate with some others at the same time, such as a study that states depression is high among illiterate parents (Sepehrmanesh, 2003, and Ramazani, 2001)¹¹.This result disagree with those findings of (Sethi, et al., 2007)who found that Parents' education status of the family didn't mark any difference to theapparent burden and stress²⁶.

Also about education level of the father the result shows that there is a significant relationship between psychological parents burden and father level of education at p value (0.012). This result corroborate with some others at the same time, such as a study that states depression is high among illiterate parents (Sepehrmanesh, 2003, and Ramazani, 2001)¹¹. This result are different from those findings of (Sethi, et al., 2007)who found that Parents' education status of the family didn't mark any difference to the apparent burden and stress²⁶.

The result also shows that there is a non-significant relationship between mother occupation and her psychologicalburden. This results supported by the findings of (Jadhav 2013) who found there was no significant co-relation was found with burden score and of the occupation of the parents or caregivers²⁵.

There is a non-significant relationship between father occupation and his psychologicalburden. These results agree with the findings of (Jadhav 2013) she found there was no significant co-relation was found with burden score and of the occupation of the parents or caregivers²⁵.

There is a non-significant relationship between social status of parents and psychologicalburden. These findings supported by with the finding of (Maheswari 2014)who found that there were no significant associations between the marital status and care giving burden of the respondents¹⁶.

There is a non-significant relationship between parent'spsychologicalburden and the person who is Provide Child Care at p value (0.882).That's maybe due to the father or mother give the same care for them child and the main sample (father and mother) are living together .

There is a significant relationship between parents psychologicalburdenandMonthly income at p value (0.027). These findings supported by the finding of (Maheswari 2014) who found that a significant association between the respondents' income and burden of care giving¹⁶.

There is significant relationship between psychological parents' burden and residency. This result disagree with (Motamedi, et al., 2007) who found that there were no significant relationship between the depression levels of the mothers with their family's housing area¹¹.

There is non-significant relationship between family members and psychologicalburden. These findings are supported by the finding of (Maheswari 2014) who found that there were no significant associations between the family members and care giving burden of the respondents⁽¹⁶⁾.

Conclusion

All parents are affected by the presence of mentally retardate children in different levels.the prevalence of burden for both mother and father are at age group (40-49) years old.There are non-significant differences between parents burden and child gender.most mental retardation children have significant relation between parents burden and mental retardation degree .

Recommendations

1. Educate the parents about the psychological effects and it's negatively impacts on their lives to face all kinds of difficult conditions in which they live from the children.
2. The study is recommended that future researches should be directed towards exploring psychological intervention factors which help to minimize the burden on parents of children with mental retardation.
3. Constructing a special program for children performing at home and in the institute in cooperation with parents
4. Establishing special institute for MR children to providing special services ton decrease parents burden.
5. Group psychotherapy education program for MR parents to increase their knowledge and experience about behavioral modification, coping strategies and stress management skill to improve their psychological wellbeing and decrease distress.

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