

## **Evaluation of Parents' Burden of Care among Children with Mental Retardation in Karbala City**

**Alya K. Abas**/ lecture/Mental Health Nursing, College of Nursing, University of Al-Qadisiyah, Iraq . [alya.abas@qu.edu.iq](mailto:alya.abas@qu.edu.iq)

**Ridha. M. Lefta / Ph.D- Assist Prof** / Community Health Nursing Department, College of Nursing, University of Al-Ameed, Karbla,Iraq . [Dr.Radha.M@alameed.edu.iq](mailto:Dr.Radha.M@alameed.edu.iq).

### **Abstract:**

**Background:**The Mental retardation (MR) is a general neurodevelopmental disorder seen as meaningfully reduction of intellectual and adaptive effect. It is called intellectual developmental impairment (IDI), general learning impairment, or Intellectual disability.

**Objectives:**To determine of parents burden of care among children with mental retardation in and to find out the relationship between level parents burden of care among children with mental retardation and their demographic data.

### **Material and Design of the study:**

A cross sectional study design was carried out of the study to achieve this study throughdetermine of parents burden of care among children with mental retardation in and to find out the relationship between level parents burden of care among children with mental retardation and their demographic data. A total of study subject are 90 parents (40 are mother and 50 are father) attending for out clinic in Karbala city were selected by purposive sample for the study.

**Results:** The study results indicate that the majority of both mother and father are (40-49) years old within age group. 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 private job. Regarding to burden parents are (45.6%) of the parents are exhibit high burdens due to the handicap among their children.

### **Conclusions:**

The conclusion most of the study participantsof 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. Regarding levels of education the burden found in read and write levels are more than others. Regarding to monthly income, the most parents have low income, and it has relation to the burden. According to who is care for the child, the most are mothers. The study concludes most of parents suffer from burden due to have child with mental retardation.

### **Recommendation:**

Educate the parents about the psychological effects and its negative impacts on their lives to face all kinds of difficult conditions in which they live from the children. 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. Constructing a special program for children performing at home and in the institute in cooperation with parents

**.Key Word:** mental retardation, parents burden, care giver, Handicap

### **INTRODUCTION:**

The parents who have child with diagnosis of mental retardation 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 life (1).

The prevalence of mental retardation is very high in developing countries mostly due to nutritional, environmental, disease burden and poverty (2).

Every father and mother experience a sense of self-respect. At the same time, they pass through an amount of stress in the process of bringing up children. Mental stress is very high among parents of mentally retarded children (3).

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 (4).

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 caregivers (5). Caregiver burden is defined as "a multidimensional response to physical, psychological, emotional, social and financial stressors usually associated with the connection with caring" (6).

As a general agreement, mental retardation can impose psychological problems, social issues, and lifestyle restrictions that can affect quality of life of the caregivers and family members, who also bear the considerable indirect costs of patients' disability. But this is only one side of the coin; there are examples where act of caregiving is found to be associated with experiencing subjective gains and satisfaction (6).

The prevalence of mental retardation is very high in developing countries mostly due to nutritional, environmental, disease burden and poverty (7).

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 levels (8).

### **Material and Design of the study:**

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data. A total of study subject are 90 parents (40 are mother and 50 are father) attending for out clinic in karbala city were selected by purposive sample for the study.

**Ethical consideration:** the study was obtained from the ethical review Committee of the collage of nursing University of AL-Ameed and collage of nursing University of Al-Qadisiyah Permission and for data and sample collection was obtained from the study subject (parents) who have children mental retardation in out clinic of mental and psychological health.

**Data collection:**

The data collection process was initiated for the period of July 1<sup>st</sup>, 2020 through August 23<sup>th</sup>, 2020. The data collection is from parents who have child mental retardation and provide care for their children and the time consumer for each interview is (20-25 minutes) with one parents.

**Instruments:**

a questionnaire was fashioned for the purpose of the study. It is composed of three major parts included personal information sheet. Demographical data, social-demographic data and clinical data such as age, period of handicap

**Analysis:**

In order to determine whether the objectives of the study were met or not, two statistical approaches were used for analyzing the data of the study by descriptive and inferential analysis.

**Results of the study:**

**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

<b>parents Occupation</b>	<b>government employee</b>	<b>6</b>	<b>15</b>	<b>13</b>	<b>26</b>
	<b>Private job</b>	<b>2</b>	<b>5</b>	<b>18</b>	<b>36</b>
	<b>free business</b>	<b>1</b>	<b>2.5</b>	<b>5</b>	<b>10</b>
	<b>Retired</b>	<b>1</b>	<b>2.5</b>	<b>13</b>	<b>26</b>
	<b>Unemployed /House wife</b>	<b>30</b>	<b>75</b>	<b>1</b>	<b>2</b>
	<b>total</b>	<b>40</b>	<b>100</b>	<b>50</b>	<b>100</b>

This table shows the study results indicate that the majority of both mother and father are (40-49) years old within age group. 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 private job.

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

<b>General information</b>	<b>rating</b>	<b>frequency</b>	<b>percentage</b>	<b>cumulative percent</b>
<b>Social Status Of Parents</b>	<b>Live Together</b>	<b>82</b>	<b>91.1</b>	<b>91.1</b>
	<b>Divorced</b>	<b>3</b>	<b>3.3</b>	<b>94.4</b>
	<b>Separated</b>	<b>5</b>	<b>5.6</b>	<b>100</b>
<b>Monthly Income</b>	<b>Sufficient</b>	<b>20</b>	<b>22.2</b>	<b>22.2</b>
	<b>Sufficient To Some Extent</b>	<b>33</b>	<b>36.7</b>	<b>58.9</b>
	<b>Insufficient</b>	<b>37</b>	<b>41.1</b>	<b>100</b>
<b>Who Is Provide ChildCare</b>	<b>Mother</b>	<b>82</b>	<b>91.1</b>	<b>91.1</b>
	<b>Father</b>	<b>8</b>	<b>8.9</b>	<b>100</b>
<b>Residency</b>	<b>Rural</b>	<b>4</b>	<b>4.4</b>	<b>4.4</b>
	<b>Countryside</b>	<b>15</b>	<b>16.7</b>	<b>21.1</b>
	<b>Urban</b>	<b>71</b>	<b>78.9</b>	<b>100</b>
<b>Number Of Handicapped Child</b>	<b>1</b>	<b>74</b>	<b>82.2</b>	<b>82.2</b>
	<b>2</b>	<b>12</b>	<b>13.3</b>	<b>95.6</b>
	<b>3</b>	<b>4</b>	<b>4.4</b>	<b>100</b>

This table shows that the study results are (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, and (82.2%) of families have one handicapped child.

**Table (3) evaluation of overall parents' burdens with children of mental retardation**

<b>Overall domain</b>	<b>Scale</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Percent</b>
<b>overall parents' burden</b>	<b>Low burdens</b>	<b>11</b>	<b>12.2</b>	<b>12.2</b>
	<b>Moderate burdens</b>	<b>38</b>	<b>42.2</b>	<b>54.4</b>
	<b>High burdens</b>	<b>41</b>	<b>45.6</b>	<b>100</b>
	<b>Total</b>	<b>90</b>	<b>100</b>	

This table shows that (45.6%) of the parents are exhibit high burdens due to the handicap among their children.

**Table (4) relationship between parents' burdens and their demographic data**

Demographic data	Rating	Overall Parents' Burrdens			Chi. sq	d. f	P. value
		Low burdens	Moderate burdens	High burdens			
Mother /age	20-29	0	2	1	11.103a	6	0.085
	30- 39	1	6	8			
	40-49	4	6	6			
	50-59	0	3	3			
Fatherage	20-29	0	2	0	8.569a	8	0.573
	30- 39	1	4	6			
	40-49	4	7	9			
	50-59	1	5	6			
	60.00+	0	3	2			
Mother level of education	illiterate	1	3	4	5.142a	8	0.742
	able to read and write	1	3	2			
	primary school graduated	1	4	6			
	secondary school graduated	2	3	2			
	college or institute	1	4	3			
Fatherlevel of education	illiterate	0	1	2	9.303a	8	0.504
	able to read and write	1	2	1			
	primary school graduated	3	4	6			
	secondary school graduated	1	7	5			
	college or institute	1	7	9			
Motheroccupation	government employee	1	3	2	8.636a	8	0.374
	Private job	0	1	1			
	free business	0	1	0			
	Retired	0	1	0			

	House wife	4	11	15			
Fatheroccupation	government employee	1	6	6	5.838a	8	0.829
	Private job	3	6	9			
	free business	0	2	3			
	Retired	2	6	5			
	unemployed	0	1	0			
Socialparents	Live Together	10	34	38	2.290a	4	0.683
	Divorced	1	1	1			
	Separated	0	3	2			
Childcare	Mother	10	34	38	.251a	2	0.882
	Father	1	4	3			
Monthlyincome	Sufficient	3	8	9	4.906a	4	0.027
	Sufficient To Some Extent	1	17	15			
	Insufficient	7	13	17			
Residency	Rural	1	2	1	1.473a	4	0.831
	Countryside	1	7	7			
	Urban	9	29	33			
Familiymembers	1-3	3	2	2	14.834a	8	0.062
	4.00 - 6.00	3	25	21			
	7.00 - 9.00	4	10	13			
	10.00 - 12.00	1	0	5			
	13.00+	0	1	0			
Childhandicap	1	8	28	38	8.733a	4	0.048
	2	2	9	1			
	3	1	1	2			

This table shows that there is a non-significant relationship between the levels of parents' burdens and their demographic data at p-value more than 0.05 except child hand cap that there is a significant at p. value less than 0.05.

### Discussion:

The results of the study indicate that 40% of parents are at age group (40-49) years old . This result agrees with the findings of <sup>(9)</sup> they found that (42%) of the participants' ranged from 40 to more than 50 years old. They also agree with<sup>(10)</sup> who found that the majority of both mother and father (50% ) are at age group(41-50) years old. Whilethese result disagree with the findings of<sup>(11)</sup> who found that (49%) of mothers at the age group (20-30 years). According to levels of education the result showsthat both mothers and fathers are primary school graduates (27.5%) and (40%)respectively. This result agrees with the findings of

<sup>(11)</sup> they found that (28%) of mothers are reading and writing and primary school graduate. Also the result agrees with the findings of <sup>(12)</sup> they found that (44%) are less than secondary educational level. While these result disagree with the findings of <sup>(13)</sup> who found that educational qualification of the parents.

The result shows that the majority (75%) of mothers are housewives, (36%) of fathers' occupation are free business. This result agrees with the findings of <sup>(13)</sup> they found that the mothers of children with mental retardation 93.3% are housewives. This result also agrees with the findings of <sup>(11)</sup> they found that 88% of the 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 <sup>(14)</sup> Who found that (50%) were married. This result agree with the findings of <sup>(15)</sup> who found that More than 50% of both parents in the study reported that no change has happened in their marital life. mothers are housewives, also the result agree with the findings of <sup>(13)</sup> they found that (80%) are Housewife.

According to the monthly income the majority of the parents (41.1%) have Insufficient income. This result agree with the findings of <sup>(16)</sup> 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 <sup>(14)</sup>.

Our result show (82.2%) of families have one handicapped child. This result agree with the finding of <sup>(16)</sup> who found that maximum of the families (above 86%) had one mentally retarded kids. While this result disagree with the findings of finders <sup>(17)</sup>.

According to parents burden levels, the results shows that high burden (45.6 %), moderate burdens (42.2%) and low burden (12.2%) due to the handicap among their children. This result are smiler those findings of <sup>(18)</sup> who found that Parents of kids with severe to profound MR had highest level of burdens and stress. The similar finding are also found by <sup>(17)</sup> They found that respondents expressed a high level of overall burden.

The result shows that no significant relation between (age and level of education) of mother and her burden (physical, psychological and economic). This result are smiler to those findings of <sup>(18)</sup> who found that Parents' education status of the family didn't mark any difference to the apparent burden and stress. These result agree with the findings of <sup>(19)</sup> who found no significant relationship of parntsburden and occupation. This result also agree with <sup>(11)</sup>.

This result is supported by the finding of <sup>(20)</sup> who indicate that rural and urban mothers had no significant difference. There is a significant relationship between parents burden and Monthly income at p value (0.027). These findings supported by the finding of <sup>(21)</sup> who found that a significant association between the respondents' income and burden of care giving. This results are disagree with those findings of <sup>(18)</sup>.

## **Conclusions**

1. The prevalence of burden for both mother and father are at age group (40-49) years old.
2. There are non-significant differences between parents burden and child gender.
3. Regarding levels of education the burden found in read and write levels are more than others. Regarding to monthly income, the most parents have low income, and it has relation to the burden.
4. According to who is care for the child, the most are mothers.
5. The study concludes most of parents suffer from burden due to have child with mental retardation.
6. The result indicates that burden are more economical burden.
7. There is significant relationship between the age of mother and the burden.

## **Recommendations:**

1. Educate the parents about the psychological effects and its negative 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 mental retardation children to providing special services to decrease parents burden.
5. Group psychotherapy education program for parents who have children with mental retardation 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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