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## BURDEN OF FAMILY CAREGIVERS FOR THE CHILDREN WITH MENTAL RETARDATION AT PORT- SAID CITY

Gehad Mohamed AboElmatty<sup>1</sup>; Naglaa Ibrahim Mohamed Gida<sup>2</sup>; Nahed  
AbdElazeem AbdEsalam<sup>3</sup>; Enas Ahmed Farag<sup>4</sup>

*Professor of Family & Community Health Nursing, Faculty of Nursing – Port-said  
University Egypt<sup>1</sup>. Assistant Professor of Family & Community Health Nursing,  
Faculty of Nursing - Port Said University Egypt<sup>2</sup>. Assistant Professor of Family &  
Community Health Nursing, Faculty of Nursing - Port Said University Egypt<sup>3</sup>*

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### ABSTRACT

**Background:** Children with mental retardation require intensive care by parents to optimize their developmental stages such as conducting medical examinations, counseling and coaching. family members are the most important part for children with mental retardation to be able to live their lives well. **Aim:** to explore burden of family caregivers for the children of mental retardation at Port-Said City. **Subjects and Method:** A descriptive cross-sectional research design was used at the only governmental schools for mental retardation in Port Said and Port Fouad city namely Intellectual Educational schools. Purposive sampling was be used. Two tools used to gather the required data consisted of; **Tool (1)** Astructured self administer questionnaire **Tool (2)** burden scale. **Results:** The study revealed that(20.0 %) of the studied family caregivers had no burden, followed by (32.2 %) of them had mild burden while (41.7 %) of them had moderate burden, and finally (6.1 %) of the studied family caregivers had sever burden. **Conclusion:** It can be concluded that about tow fifth of the studied family caregivers had moderate level of burden. **Recommendations:** Designing and training program to caregivers regarding coping and rehabilitation for their roles to their mentally retarded children. Special financial support should be given to these families to help them to meet extra demands and costs of caring their mental retarded children.

**Keywords:** Burden, family caregivers, mental retardation

## INTRODUCTION

Mental retardation (MR) is a source of pain to many families. The idea of MR is considered one of the serious problems that gravely concern the government in Egypt as well as all over the world, it can be found as back in history as around and fifty-four mentally retarded children in Egypt (World Health Statistics, 2015).

The etiologies of mental retardation are multiple; this can be influenced by social, economic, cultural, racial, ethnic and other environmental factors including the demographics of age and gender. Various studies have consistently found the prevalence of mental retardation to be associated with a low socioeconomic status (Chouhan, Singh, & Kumar, 2016 ).

On the basis of the nature of the factors, causes may be classified as environmental and genetic. Environmental causes can affect a child *viapre-* and postnatal exposures. There are numerous environmental factors that often contribute to mental retardation. Toxins such as lead and mercury affect mental health. Iodine deficiency affecting about 2 billion people all over the world is the leading preventable cause of mental disability in areas of the developing world where iodine deficiency is endemic. Lack of adequate availability of iodine from the mother restricts the growth of the brain of the fetus and leads to a condition called neonatal hypothyroidism (Sharma et al ,2016).

All family caregivers wish for a healthy child, but some caregivers not by their choice are gifted with mental retarded children. Caring of mental retarded child is not an easy task. Family caregivers having mental retarded child experience a variety of psychological stresses related to the child's disability. Family caregivers especially mothers' need every help and encouragement possible in their difficult task, which is indeed easier for them while the child is still a baby (Rajan, & John, 2017).

Family caregiver Broadly defined, refers to any relative, partner, friend, or neighbor who has a significant personal relationship with, and who provides a broad range of assistance for, children with mental retardation and serious health condition (Reinhard e t al , 2015). The family constitutes a major support system of the continuing care of the mental retarded children in the community. Although many families show a strong resilience of caring for an ill relative. This share of physical and emotional distress cannot be ignored (Kamel, 2014).

Burden of family caregiver is any unwanted or negative consequences experienced by caregivers of people with mental illness as a result of taking care of responsibility for mental retarded children. It can be either objective burden such as family disruption, financial crisis, limitations on activities of daily living and social interactions, and subjective burden which is a perceived feeling of getting overwhelmed by the care they are providing. In general, burden among caregivers encompasses physical, psychological, emotional, social, and financial difficulties that family members faced because of taking care of responsibility for mental retarded children (Ayalew et al, 2019).

The treatment and rehabilitation of clients with mentally retarded children are regarded as a heavy burden for every government and family. Raising a child who is mentally challenged requires emotional strength and flexibility. The child has special needs in addition to the regular needs of all children and caregivers can find themselves overwhelmed by various medical care giving and educational responsibilities. Whether special needs of the child are minimal or complex, the caregivers lack support from family, friends, community or paid care givers and is critical to maintain balance in the home care giver burden is a term used to describe the physical, emotional and financial duty of providing care to the needy (Maheshwari, 2014).

Community health nurse should be aware of the contents and recommendations of the guidelines that can aid in improving support for caregivers. The caregiver need help addressing, and caregiver's self-care. Self-care includes healthy living recommendations, exercise, nutrition, managing caregiver's own health, and external support (Grant, et al, 2013, July). Community health nurse should make Screening, assessment, and monitoring of the degree of burden associated with caregiving are essential (Given, Sherwood ,2012) .

### **Significance of this study**

The prevalence of mental retardation in Egypt according to the central Authority for public Mobilization and statistics there are approximately two million persons with disabilities, which represents about 3.5% in 2012 of total population(El-Ganzory, El Matty & AbdelRahman, 2013).

The World Health Organization (WHO) estimates that globally over 450 million people suffer from mental disorders. Currently, mental and behavioral disorders account for 12% of the global burden of disease. This is likely to increase to 15% by 2020. The major proportions of mental disorders come from low- and middle-income countries. The

problem is further complicated by a lack of adequately trained manpower and a low priority of mental health in health policy (Sharma et al , 2016).

According to *Caregiving in the US 2015*, about 3.7 million family caregivers provided care to a child under age 18 because of a medical, behavioral, or other condition or disability and 6.5 million family caregivers assisted both adults and children. Estimates show 3.5 million individuals with intellectual or developmental disabilities (I/DD) live with family caregivers, of whom over 850,000 are age 60+( Reinhard, Feinberg, Choula, & Houser, 2015 ).

The mental retardation is one of the most frequently encountered and distressing disabilities among children in developing countries and it constitutes a major problem in Egypt because it affects the quality of life of persons and the welfare of their family (El-Ganzory, El Matty & AbdelRahman, 2013). In other hand, Families of mentally retarded children experience a lot of physical, social, emotional, economical and psychosocial problems while dealing with the disabled child. Caregivers of these disabled children face many difficulties throughout their life. They did not get enough time for themselves also. They lost all the social interactions and they feel like an out stander in the society (Darsana &Suresh, 2017). It is important understood the outcome impact on the families for child with mental retardation the understanding of types of burden will help to get benefit for both the caregivers and the mentally retarded children to provide necessary support. So, the study will be carried out to assess burden of family caregivers for the children with mental retardation in port said city.

## **AIM OF STUDY**

Explore burden of family caregivers for the children with mental retardation at Port-Said City.

### **Research Objectives Are To:**

- 1) Determine the physical burden of family caregivers.
- 2) Identify the psychological burden of family caregivers.
- 3) Asses social and economic burden of family caregivers.

## **SUBJECTS AND METHOD:**

### **I. TECHNICAL DESIGN**

Technical design includes a description of the research design, setting, subjects and tools for data collection.

**Research Design:**

Descriptive cross-sectional research design was used

**Setting:**

The study was conducted in a two Intellectual Education schools, one in Port Said city and the second in Port Fouad city.

**Sample:**

Purposive sample was done and 180 caregivers of mental retarded children will be included.

**Criteria of sample****Inclusion criteria for sampling:-**

- 1) Family caregivers living with and caring for children with mental retardation.
- 2) Family caregiver does not suffer from mental illness.
- 3) Both male and female.

**Tools of data collection:-**

Two tools was used to measure the current study concepts:

**Tool I: A structured self administrative questionnaire:**

Structured sheet was designed by the researcher in Arabic language which will be collected from caregivers. This tool include two parts.

**Part I:**

Personal or demographic characteristic of family caregivers include age, sex, marital status, level of education, occupation, income, number of children, diseases of caregivers and relation between child and caregiver.

**Part II:**

- History of mental retarded children such as degree of disability IQ, time for discovery of disability, types of relatives, causes of disability and types of disability.
- Daily living activity of child such as eating, sleeping, drinking, bathing, brush teeth & comb hair, wearing clothes & shoes and urination & defecation.
- Educational performance such as having a computer, ways of studying, ways of helping in studying, family receiving economic support and intellectual education schools.

**Tool II: Zarit Care Giver Burden scale:**

It was developed by Zarit, , Anthony, Boutselis, (1987).It consists of 22 self-report items will be used to assess the burden experienced by the care givers of mentally retarded children, examining caregivers' concern for physical, mental, social and economic aspects of caregiving. Each item will be measured on 5-point Likert - scale range from "0" to "4" as: Never (0), Rarely (1), Sometimes (2), Quite Frequently (3), Nearly Always (4).

### **Scoring System**

The total score ranges from 0 to 88. Scoring system as the following:( 0 – 20) as a little or no burden, (21 – 40) as a mild to moderate burden, (41 – 60) as a moderate burden, (61 – 88) as a severe burden. This tool is already in English language and translated into Arabic language by (To'meh, 2013).

## **II. OPERATIONAL DESIGN:**

The operational design contains the preparatory phase, validity& reliability, pilot study and fieldwork.

### **Preparatory phase:**

It included extensive review of the current national and international related literatures, different studies and theoretical knowledge of various aspects of the problems using books, research articles, internet, periodicals and magazines about studies related to the burden of family caregivers for the children with mental retardation.

### **validity:**

**The tool(1)** was reviewed by panel of seven experts , five experts in the field of family&community health nursing and two experts in the field of psychiatric health nursing to make sure that the study tool looked through its measuring and check its translation . **The tool(2)** was developed and translated to Arabic by To'meh, 2013.

### **Reliability:**

Studies of the original scale version, which include the assessment of its internal consistency with different subjects, obtained good results, with Cronbach's alpha index varying from 0.79 to 0.91. The test - retest of the scale's original version was conducted and obtained a good result (alpha=0.71) (Zarit et al., 1987).

### **Pilot Study:**

The pilot study was undertaken after the development of tool and before data collection .It was carried out on 10% of the study sample which include (18 family caregivers) of the intellectual education school which were selected randomly from each school (14 family caregivers) from port said and (4 family caregivers) from port Fouad. The purposes of the pilot study were to test the clarity, applicability, the feasibility of the study tools and to estimate the time needed to fill in the tools. According to pilot study results, necessary modifications will be done. The pilot study subjects were included from the total study sample It was conducted over a period of one month from the beginning of February to the beginning of march 2019.

**Fieldwork:**

Before beginning collection of data, an agreement of Intellectual Education schools director at port said was obtained, this step take one month at January (2018).The managers of each studied schools were informed about the purpose of the study and then taken their oral consent to conduct the study. The tools were filled from family caregivers using the interview method by the researcher after explaining the purpose of the study and trusting relationship with the studied family caregivers. The study was conducted on two Intellectual Education schools. The researcher selected all family caregivers who attend to school with children.They were assured that the information given would be treated with confidentiality and used for the research purpose. Also they were given an opportunity to refuse to participate. The purpose of the study was explained to each family caregivers prior answering the questionnaire sheet, then an oral consent was obtained from them. The researcher know and determine the suitable time to the family caregivers from the manager of each school. During interview of data collection, each items and questions of collection sheet was explained by the researcher to the participant family caregivers. The total time permitted to achieve it by researcher ranges from 20 to 30 minutes to collaborate. The actual field of work was carried out from the beginning of March (2018) to the end of April(2019). Collected data from one Intellectual Education school per three days per week as the following: Intellectual Education school in port said on Sunday and Monday, Intellectual Education school in port Fouad on Thursday, from 9am to 2 pm. The average number of family caregivers token per day was(5-10) caregivers at each time data collection. The present study consumed about 9 months, five months of them for obtaining the official permission, modification of the tools, pilot study and test clarity and feasibility of the tools. The next two months consumed for data collection while, the last two months for data entry and statistical analysis.

**ADMINISTRATIVE DESIGN:**

Before starting any step in the study, an official letter will be issued from the Dean of the faculty of nursing to the director of Port Said Intellectual Education, schools will be contacted and informed in requesting his cooperation and permission to conduct the study in Intellectual Education schools.

**Ethical Considerations:**

Once the agreement was approved to proceed with the present study from responsible and influential managers at Intellectual Education schools, the researcher started data collection and communicated each possible family caregiver to explain the aim and nature of the study. Moreover, the process of data collection did not interrupt the harmony of the

work. The researcher stressed that contribution in the study is completely voluntary; the confidentiality of their answers was guaranteed. The researcher presented herself to family caregivers who encountered the inclusion criteria; the goal of the study was clarified. Oral consent was taken from family caregivers who accepted involvement in the study and the importance of his/ her participation. The researcher emphasized that each family caregivers has the right to withdraw from the study at any period without illuminating any reasons.

### III. STATISTICAL DESIGN:

Collected data were coded, computed and statistically analyzed using SPSS (statistical Package of social sciences), version 16. Data were presented as frequency and Percentages (qualitative variables) and mean  $\pm$  SD or median (quantitative continuous Variables). For continuous quantitative variables which were not normally distributed, Median was used as a central tendency measures and Mann Whitney test (Z) was used for comparison of two groups and Kruskal-Wallis ( $\chi^2$ ) test for comparison of more than two groups. Spearman's correlation was used to find correlation between two variables. The difference was considered significant at  $P \leq 0.05$ .

### RESULTS:

**Table(1):** revealed that 36.2 % of family caregivers age ranges between 35-44 years old. While , 67.8% of them were female. Looking to their level of education, it is found that 25.0% of them had university level. While only 0.6% had post graduate studies level of education. It is also observed that 70.6% of family caregivers were married, 56.1% of them had sufficient income. Concerning number of family members, the table showed that 37.8% of the caregivers had four family members. The 80.6% of them were worked. **The table** illustrate that 70.6% of mental retarded children stated to live with father and mother, while 0.6% of them lived with their sister, brother and father. As the table showed 37.8% of studied family caregivers have two sons and 37.2% of studied mental retarded children were the second child.

**Table(2):** showed that 62.2% of studied mental retarded children were able to eating and drinking by themselves. It is also observed that 66.7% of them were able to bathing by themselves, while 31.1% of them were need partial help . mental retarded children 43.3% had always sleep alone. On the other hand, mental retarded children 57.2% were need partial help on brush teeth and comb hair. In addition, 65.6% of them were need partial help on wearing clothes and shoes. Also, 66.1% of mental retarded children were depended on themselves on urination and defecation, while 30.6% of them need partial help.

**Table (3):** revealed that 38.9% of family caregivers were sometimes feel they have lost control of their life since their relative's illness, while 30.6% of them were rarely feel stressed between caring for their relative and trying to meet other responsibilities for their family or work. Also, 45.0% of them were sometimes feel stressed between caring for their relative and trying to meet other responsibilities for their family or work. In addition, 25.0% of them were frequently feel strained when they are around their relative and 7.8% of them were always afraid what the future holds for their relative. Regarding economic burden, 47.2% of them were sometimes feel that they do not have enough money to take care for their relative in addition to the rest of your expenses.

**Table (4):** illustrates that 41.7% of family caregivers were sometimes feel that their relative currently affects their relationships with other family members or friends in negative way and feel that their social life has suffered because they are caring for their relative. Results shows that 41.7% of them were sometimes Overall, burden do they feel in caring for their relative, 44.4% of them were sometimes feel their health has suffered because of their involvement with their relative .In addition , 21.1% of them were frequently feel uncomfortable about having friends over because of their relative, while 5.6% of them always feel their health has suffered because of their involvement with their relative.

**Table (5):** show that 30.0 % of studied family caregivers were sometimes wish they could leave the care of their relative to someone else, 38.3% of them were sometimes feel that because of the time they spend with their relative that they don't have enough time for themselves. 48.3% of them were sometimes feel that their relative asks for their help than he/she needs, 26.7% of them were frequently feel they should be doing more for their relative. 5.6% of them were always feel embarrassed over their relative's behavior and feel they could do better job in caring for their relative. 45.6% of them were sometimes feel their relative were dependent on them.

**Figure (1):** illustrates levels of burden scale as reported by the studied family caregivers ,As the table shows 20.0 % of the studied family caregivers had no burden ,followed by 32.2 % of them had mild burden while 41.7 % of them had moderate burden and finally 6.1 % of the studied family caregivers had sever burden.

**Table (6):** illustrates relation between personal characteristics of studied family caregivers and levels of burden scale. The table presented that, 17.2 % of the studied family caregivers at age ranged 45-54 years had moderate burden. While, 2.2% of them at age ranged 35-44 and 45-54 had sever burden. there was a statistically significant difference

between age of studied family caregivers and levels of burden scale where ( $p=0.003$ ). Regarding income, 22.8 % of studied family caregivers who have sufficient income had moderate burden. While, only 1.1% had sever burden. there was a statistically significant difference between income of studied family caregivers and levels of burden scale where( $p=0.000$ ). There was a statistically significant difference between child live with father and mother and levels of burden scale where( $p=0.027$ ). on the other hand, the same table detects that there is no statistically significant relation between level of burden among studied family caregivers and sex ,education, marital status ,number of family member and job.

**Table (7):** illustrates that 21.7% of studied mental retarded children depend on themselves in eating and drinking had moderate burden and 1.1% of them need help of family member in eating and drinking had sever burden. There was a statistically significant relation between depend on themselves in eating and drinking of studied mental retarded children and levels of burden ( $p=0.007$ ). There was a statistically significant relation between levels of burden and the mental retarded children need partial help in bathing ( $p=0.001$ ), brush teeth&comb hair ( $p=0.026$ ) and need help of others in urination and defecation ( $p=0.043$ ). However, it was founded that There was no statistically significant relation between levels of burden and wearing clothes&shoes.

**Table (1):** Personal Characteristics of the family care givers (n=180):

| items              | Studied sample(n=180) |      |
|--------------------|-----------------------|------|
|                    | No                    | %    |
| <b>Age (years)</b> |                       |      |
| <25                | 8                     | 4.4  |
| 25-                | 27                    | 15.0 |
| 35-                | 65                    | 36.2 |
| 45-                | 62                    | 34.4 |
| 55-                | 17                    | 9.4  |
| >65                | 1                     | 0.6  |
| <b>Sex</b>         |                       |      |
| Males              | 58                    | 32.2 |
| Females            | 122                   | 67.8 |
| <b>Education</b>   |                       |      |
| Illiterate         | 33                    | 18.3 |
| Primary            | 25                    | 13.9 |
| Preparatory        | 32                    | 17.8 |
| Secondary          | 44                    | 24.4 |
| University         | 45                    | 25.0 |
| Post               | 1                     | 0.6  |

|                                 |     |      |
|---------------------------------|-----|------|
| <b>Marital status</b>           |     |      |
| Single(sister or brother)       | 3   | 1.7  |
| Widow                           | 30  | 16.7 |
| Married                         | 127 | 70.6 |
| Divorced                        | 20  | 11.1 |
| <b>Income</b>                   |     |      |
| Sufficient                      | 101 | 56.1 |
| Insufficient                    | 79  | 43.9 |
| <b>Number of family members</b> |     |      |
| Two                             | 10  | 5.6  |
| Three                           | 47  | 26.1 |
| Four                            | 68  | 37.8 |
| Five                            | 38  | 21.1 |
| >Five                           | 17  | 9.4  |
| <b>Occupation status</b>        |     |      |
| Not working                     | 35  | 19.4 |
| Working                         | 145 | 80.6 |
| <b>child live with</b>          |     |      |
| Father & mother                 | 127 | 70.6 |
| Father                          | 5   | 2.8  |
| Mother                          | 37  | 20.6 |
| Brother                         | 1   | 0.6  |
| Sister                          | 3   | 1.7  |
| Father & sister                 | 1   | 0.6  |
| Others(grand pa,grandma)        | 6   | 3.3  |
| <b>Number of sons</b>           |     |      |
| One                             | 22  | 12.2 |
| Two                             | 68  | 37.8 |
| Three                           | 59  | 32.8 |
| >three                          | 31  | 17.2 |
| <b>Child order</b>              |     |      |
| First                           | 66  | 36.7 |
| Second                          | 67  | 37.2 |
| Third                           | 32  | 17.8 |
| Fourth & more                   | 15  | 8.3  |

**Table (2):** Daily activities of the mental retarded children (n=180):

| Items                             | Studied sample(n=180) |      |
|-----------------------------------|-----------------------|------|
|                                   | No                    | %    |
| <b>Eating &amp; Drinking</b>      |                       |      |
| Independant                       | 112                   | 62.2 |
| Partial                           | 59                    | 32.8 |
| Dependant                         | 9                     | 5.0  |
| <b>Bathing</b>                    |                       |      |
| Depend on himself                 | 120                   | 66.7 |
| Need partial help                 | 56                    | 31.1 |
| Need complete help                | 4                     | 2.2  |
| <b>Sleep alone</b>                |                       |      |
| Always                            | 78                    | 43.3 |
| Sometimes                         | 76                    | 42.3 |
| Partially                         | 26                    | 14.4 |
| <b>Brush teeth&amp; comb hair</b> |                       |      |
| Depend on himself                 | 71                    | 39.4 |
| Need partial help                 | 103                   | 57.2 |
| Depend totally on others          | 6                     | 3.3  |
| <b>Wearing clothes &amp;shoes</b> |                       |      |
| Depend on himself                 | 51                    | 28.3 |
| Need partial help                 | 118                   | 65.6 |
| Depend totally on others          | 11                    | 6.1  |
| <b>Urination&amp; Defecation</b>  |                       |      |
| Depend on himself                 | 119                   | 66.1 |
| Need partial help                 | 55                    | 30.6 |
| Depend totally on others          | 6                     | 3.3  |

**Table (3):** Study sample of caregivers according to Psychological & Economic burden scale of family care givers of their mental retarded children (n=180):

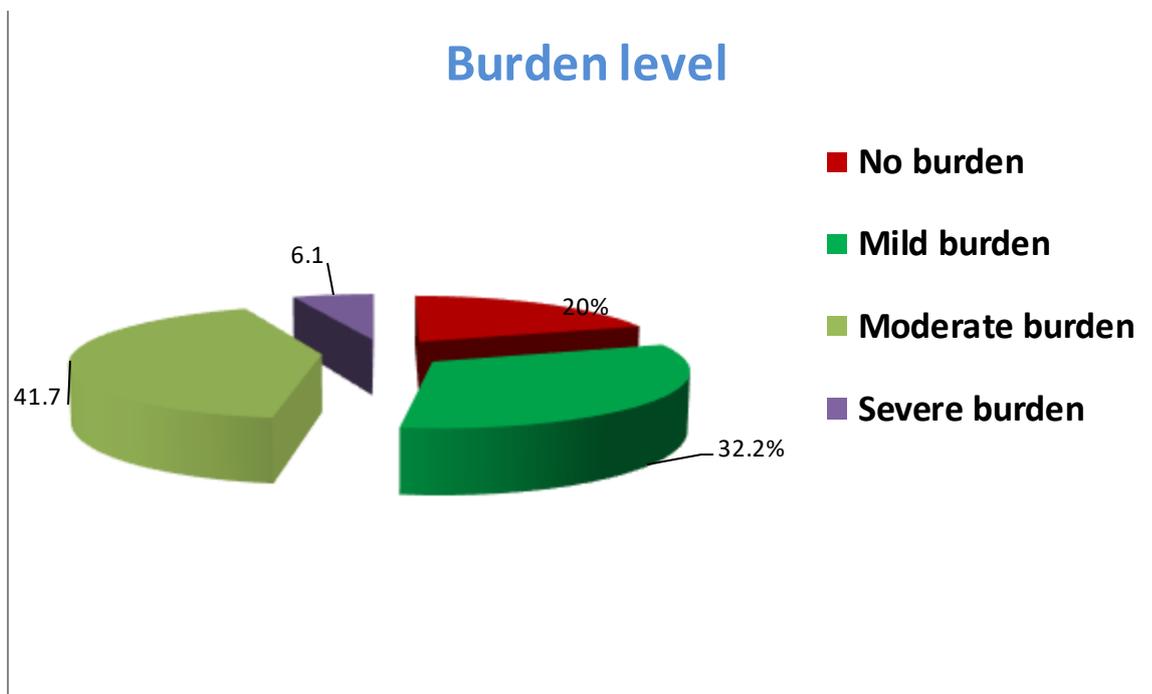
| Items   | Never |      | Rarely |      | Some times |      | Frequentl<br>y |      | Always |     | Averag<br>e Score |
|---|-------|------|--------|------|------------|------|----------------|------|--------|-----|-------------------|
|   | No.   | %    | No.    | %    | No.        | %    | No.            | %    | No.    | %   |                   |
| A- Psychological burden   |       |      |        |      |            |      |                |      |        |     |                   |
| feel stressed between caring for your relative and trying to meet other responsibilities for your family or work. | 24    | 13.3 | 55     | 30.6 | 81         | 45.0 | 12             | 6.7  | 8      | 4.4 | 1.58<br>±0.96     |
| feel anger when you are around your relative.   | 38    | 21.1 | 48     | 26.7 | 62         | 34.4 | 31             | 17.2 | 1      | 0.6 | 1.49<br>±1.03     |
| afraid what the future holds for your relative.   | 34    | 18.9 | 31     | 17.2 | 59         | 32.8 | 42             | 23.3 | 14     | 7.8 | 1.84<br>±1.20     |
| feel strained when you are around your relative   | 46    | 25.6 | 33     | 18.3 | 49         | 27.7 | 45             | 25.0 | 1      | 0.6 | 1.63<br>±1.21     |
| feel you have lost control of your life since your relative's illness   | 47    | 26.1 | 36     | 20.0 | 70         | 38.9 | 24             | 13.3 | 3      | 1.7 | 1.44<br>±1.07     |
| feel uncertain about what to do about your relative   | 38    | 21.1 | 32     | 17.8 | 67         | 37.2 | 40             | 22.2 | 3      | 1.7 | 1.66<br>±1.10     |
| B- Economic burden  |       |      |        |      |            |      |                |      |        |     |                   |
| feel that you do not have enough money to take care for your relative in addition to the rest of your expenses    | 27    | 15.0 | 33     | 18.3 | 85         | 47.2 | 26             | 14.4 | 9      | 5.0 | 1.76<br>±1.04     |

**Table (4):** Study sample of caregivers according to Social & physical burden scale of family care givers of their mental retarded children (n=180):

| Items  | Never |      | Rarely |      | Some times |      | Frequentl<br>y |      | Always |     | Averag<br>e Score |
|--|-------|------|--------|------|------------|------|----------------|------|--------|-----|-------------------|
|  | No.   | %    | No.    | %    | No.        | %    | No.            | %    | No.    | %   |                   |
| C. Social burden   |       |      |        |      |            |      |                |      |        |     |                   |
| 1. feel that your relative currently affects your relationships with other family members or friends in negative way | 39    | 21.7 | 41     | 22.8 | 75         | 41.7 | 22             | 12.2 | 3      | 1.7 | 1.44<br>±1.02     |
| 2. feel that your social life has suffered because you are caring for your relative                                  | 39    | 21.7 | 37     | 20.6 | 65         | 36.1 | 38             | 21.1 | 1      | 0.6 | 1.58<br>±1.06     |
| 3. feel uncomfortable about having friends over because of your relative   | 34    | 18.9 | 40     | 22.2 | 66         | 36.7 | 38             | 21.1 | 2      | 1.1 | 1.63<br>±1.05     |
| D. physical burden   |       |      |        |      |            |      |                |      |        |     |                   |
| 1. feel your health has suffered because of your involvement with your relative                                      | 30    | 16.7 | 39     | 21.7 | 80         | 44.4 | 21             | 11.7 | 10     | 5.6 | 1.68<br>±1.06     |
| 2. Overall, burden do you feel in caring for your relative   | 19    | 10.6 | 45     | 25.0 | 75         | 41.7 | 35             | 19.4 | 6      | 3.3 | 1.80<br>±0.98     |

**Table (5)** Study sample of caregivers according to relation burden scale between family care givers and mental retarded children (n=180):

| Items  | Never |      | Rarely |      | Some times |      | Frequently |      | Always |     | Average Score |
|--|-------|------|--------|------|------------|------|------------|------|--------|-----|---------------|
|  | No.   | %    | No.    | %    | No.        | %    | No.        | %    | No.    | %   |               |
| 1. feel that your relative asks for your help than he/she needs  | 23    | 12.8 | 39     | 21.7 | 87         | 48.3 | 29         | 16.1 | 2      | 1.1 | 1.71<br>±0.92 |
| 2. feel that because of the time you spend with your relative that you don't have enough time for yourself             | 12    | 6.7  | 53     | 29.4 | 69         | 38.3 | 43         | 23.9 | 3      | 1.7 | 1.84<br>±0.92 |
| 3. feel embarrassed over your relative's behavior  | 35    | 19.4 | 38     | 21.1 | 66         | 36.7 | 31         | 17.2 | 10     | 5.6 | 1.68<br>±1.13 |
| 4. feel your relative is dependent on you  | 20    | 11.1 | 36     | 20.0 | 82         | 45.6 | 35         | 19.4 | 7      | 3.9 | 1.85<br>±0.99 |
| 5. feel that you don't have as much privacy as you would like because of your relative                                 | 29    | 16.1 | 47     | 26.1 | 76         | 42.2 | 26         | 14.4 | 2      | 1.1 | 1.58<br>±0.96 |
| 6. feel that your relative seems to expect you to take care of him as if you were the only one, he/she could depend on | 22    | 12.2 | 41     | 22.8 | 79         | 43.9 | 29         | 16.1 | 9      | 5.0 | 1.79<br>±1.02 |
| 7. feel that you will be unable to take care of your relative much longer  | 42    | 23.3 | 40     | 22.2 | 59         | 32.8 | 32         | 17.8 | 7      | 1.9 | 1.57<br>±1.14 |
| 8. wish you could leave the care of your relative to someone else  | 61    | 33.9 | 42     | 23.3 | 54         | 30.0 | 22         | 12.2 | 1      | 0.6 | 1.22<br>±1.06 |
| 9. feel you should be doing more for your relative   | 30    | 16.7 | 26     | 14.4 | 69         | 38.3 | 48         | 26.7 | 7      | 3.9 | 1.87<br>±1.11 |
| 10. feel you could do better job in caring for your relative   | 28    | 15.6 | 20     | 11.1 | 78         | 43.3 | 44         | 24.4 | 10     | 5.6 | 1.93<br>±1.10 |



**Figure (1):** Distribution of the study sample according to levels of burden evaluation scale of the family caregivers (n=180)

**Table (6):** Relation between level of burden scale and personal characteristics of the studied family caregivers(n=180).

| Items                  | no burden |      | mild burden |      | moderate burden |      | severe burden |     | Significance test | P value |
|------------------------|-----------|------|-------------|------|-----------------|------|---------------|-----|-------------------|---------|
|                        | No        | %    | No          | %    | No              | %    | No            | %   |                   |         |
| <b>Age (years)</b>     |           |      |             |      |                 |      |               |     |                   |         |
| <25                    | 1         | 0.6  | 7           | 3.9  | 0               | 0    | 0             | 0   | $\chi^2=34.65$    | 0.003*  |
| 25-                    | 9         | 5.0  | 8           | 4.4  | 7               | 3.9  | 3             | 1.7 |                   |         |
| 35-                    | 14        | 7.8  | 24          | 13.3 | 23              | 12.8 | 4             | 2.2 |                   |         |
| 45-                    | 12        | 6.7  | 15          | 8.3  | 31              | 17.2 | 4             | 2.2 |                   |         |
| 55-                    | 0         | 0    | 3           | 1.7  | 14              | 7.8  | 0             | 0   |                   |         |
| >65                    | 0         | 0    | 1           | 0.6  | 0               | 0    | 0             | 0   |                   |         |
| <b>Sex</b>             |           |      |             |      |                 |      |               |     | Z=2.97            | 0.396   |
| Males                  | 10        | 5.6  | 17          | 9.4  | 29              | 16.1 | 2             | 1.1 |                   |         |
| Females                | 26        | 14.4 | 41          | 22.8 | 46              | 22.8 | 9             | 5.0 |                   |         |
| <b>Education</b>       |           |      |             |      |                 |      |               |     | $\chi^2=22.67$    | 0.091   |
| Illiterate             | 3         | 1.7  | 8           | 4.4  | 19              | 10.6 | 3             | 1.7 |                   |         |
| Primary                | 4         | 2.2  | 7           | 3.9  | 13              | 7.2  | 1             | 0.6 |                   |         |
| Preparatory            | 6         | 3.3  | 12          | 6.7  | 13              | 7.2  | 1             | 0.6 |                   |         |
| Secondary              | 7         | 3.9  | 13          | 7.2  | 19              | 10.6 | 5             | 2.8 |                   |         |
| University             | 15        | 8.3  | 18          | 10.0 | 11              | 6.1  | 1             | 0.6 |                   |         |
| Post                   | 1         | 0.6  | 0           | 0    | 0               | 0    | 0             | 0   |                   |         |
| <b>Marital status</b>  |           |      |             |      |                 |      |               |     | $\chi^2=10.07$    | 0.345   |
| Single(sister,brother) | 1         | 0.6  | 2           | 1.1  | 0               | 0    | 0             | 0   |                   |         |
| Widow                  | 8         | 4.4  | 7           | 3.9  | 15              | 8.3  | 0             | 0   |                   |         |
| Married                | 26        | 14.4 | 42          | 23.3 | 50              | 27.8 | 9             | 5.0 |                   |         |
| Divorced               | 1         | 0.6  | 7           | 3.9  | 10              | 5.6  | 2             | 1.1 |                   |         |

|                                 |    |      |    |      |    |      |   |     |                        |        |  |
|---------------------------------|----|------|----|------|----|------|---|-----|------------------------|--------|--|
| <b>Income</b>                   |    |      |    |      |    |      |   |     |                        |        |  |
| Sufficient                      | 30 | 16.7 | 35 | 19.4 | 34 | 18.9 | 2 | 1.1 | Z=<br>21.21            | 0.000* |  |
| Insufficient                    | 6  | 3.3  | 23 | 12.8 | 41 | 22.8 | 9 | 5.0 |                        |        |  |
| <b>Number of family members</b> |    |      |    |      |    |      |   |     | $\chi^2=$<br>13.9<br>6 | 0.303  |  |
| Two                             | 0  | 0    | 6  | 3.3  | 3  | 1.7  | 1 | 0.6 |                        |        |  |
| Three                           | 9  | 5.0  | 15 | 8.3  | 22 | 12.2 | 1 | 0.6 |                        |        |  |
| Four                            | 19 | 10.6 | 22 | 12.2 | 23 | 12.8 | 4 | 2.2 |                        |        |  |
| Five                            | 4  | 2.2  | 11 | 6.1  | 19 | 10.6 | 4 | 2.2 |                        |        |  |
| >Five                           | 4  | 2.2  | 4  | 2.2  | 8  | 4.4  | 1 | 0.6 |                        |        |  |
| <b>Occupation status</b>        |    |      |    |      |    |      |   |     | Z=<br>5.42             | 0.144  |  |
| Not working                     | 5  | 2.8  | 17 | 9.4  | 11 | 6.1  | 2 | 1.1 |                        |        |  |
| Working                         | 31 | 17.2 | 41 | 22.8 | 64 | 35.6 | 9 | 5.0 |                        |        |  |
| <b>child live with</b>          |    |      |    |      |    |      |   |     | $\chi^2=$<br>31.2<br>3 | 0.027* |  |
| Father & mother                 | 27 | 15.0 | 45 | 35.0 | 46 | 25.6 | 9 | 5.0 |                        |        |  |
| Father                          | 0  | 0    | 1  | 0.6  | 4  | 2.2  | 0 | 0   |                        |        |  |
| Mother                          | 9  | 5.0  | 7  | 3.9  | 20 | 11.1 | 1 | 0.6 |                        |        |  |
| Brother                         | 0  | 0    | 0  | 0    | 1  | 0.6  | 0 | 0   |                        |        |  |
| Sister                          | 0  | 0    | 1  | 0.6  | 2  | 1.1  | 0 | 0   |                        |        |  |
| Father & sister                 | 0  | 0    | 0  | 0    | 0  | 0    | 1 | 0.6 |                        |        |  |
| Others(grand pa,grand ma)       | 0  | 0    | 4  | 2.2  | 2  | 1.1  | 0 | 0   |                        |        |  |
| <b>Number of sons</b>           |    |      |    |      |    |      |   |     | $\chi^2=$<br>12.5<br>1 | 0.186  |  |
| One                             | 3  | 1.7  | 10 | 5.6  | 8  | 4.4  | 1 | 0.6 |                        |        |  |
| Two                             | 20 | 11.1 | 23 | 12.8 | 22 | 12.2 | 3 | 1.7 |                        |        |  |
| Three                           | 8  | 4.4  | 19 | 10.6 | 27 | 15.0 | 5 | 2.8 |                        |        |  |
| >three                          | 5  | 2.8  | 6  | 3.3  | 18 | 10.0 | 2 | 1.1 |                        |        |  |
| <b>Child order</b>              |    |      |    |      |    |      |   |     | $\chi^2=$<br>13.4<br>4 | 0.144  |  |
| First                           | 12 | 6.7  | 28 | 15.6 | 20 | 11.1 | 6 | 3.3 |                        |        |  |
| Second                          | 17 | 9.4  | 18 | 10.0 | 28 | 15.6 | 4 | 2.2 |                        |        |  |
| Third                           | 4  | 2.2  | 9  | 5.0  | 19 | 10.6 | 0 | 0   |                        |        |  |
| Fourth & more                   | 3  | 1.7  | 3  | 1.7  | 8  | 4.4  | 1 | 0.6 |                        |        |  |

**Table (7):** Relation between daily activities of studied mental retarded children and levels of burden (n=180).

| Items                             | no burden |      | mild burden |      | moderate burden |      | severe burden |     | Significance test      | P value |
|-----------------------------------|-----------|------|-------------|------|-----------------|------|---------------|-----|------------------------|---------|
|                                   | No        | %    | No          | %    | No              | %    | No            | %   |                        |         |
| <b>Eating &amp; Drinking</b>      |           |      |             |      |                 |      |               |     | $\chi^2=$<br>17.7<br>2 | 0.007*  |
| -Independant                      | 32        | 17.8 | 32          | 17.8 | 39              | 21.7 | 9             | 5.0 |                        |         |
| - partial                         | 4         | 2.2  | 22          | 12.2 | 31              | 17.2 | 2             | 1.1 |                        |         |
| -Dependant                        | 0         | 0    | 4           | 2.2  | 5               | 2.8  | 0             | 0   |                        |         |
| <b>Bathing</b>                    |           |      |             |      |                 |      |               |     | $\chi^2=$<br>21.5<br>2 | 0.001*  |
| Depend on himself                 | 34        | 18.9 | 37          | 20.6 | 41              | 22.8 | 8             | 4.4 |                        |         |
| Need partial help                 | 2         | 1.1  | 21          | 11.7 | 30              | 16.7 | 3             | 1.7 |                        |         |
| Need complete help                | 0         | 0    | 0           | 0    | 4               | 2.2  | 0             | 0   |                        |         |
| <b>Sleep alone</b>                |           |      |             |      |                 |      |               |     | $\chi^2=$<br>15.0<br>6 | 0.020*  |
| Always                            | 21        | 11.7 | 17          | 9.4  | 34              | 18.9 | 6             | 3.3 |                        |         |
| Sometimes                         | 15        | 8.3  | 31          | 17.2 | 26              | 14.4 | 4             | 2.2 |                        |         |
| Partially                         | 0         | 0    | 10          | 5.6  | 15              | 8.3  | 1             | 0.6 |                        |         |
| <b>Brush teeth&amp; comb hair</b> |           |      |             |      |                 |      |               |     | $\chi^2=$<br>14.3<br>9 | 0.026*  |
| Depend on himself                 | 20        | 11.1 | 16          | 8.9  | 28              | 15.6 | 7             | 3.9 |                        |         |
| Need partial help                 | 16        | 8.9  | 41          | 22.8 | 43              | 23.9 | 3             | 1.7 |                        |         |
| Depend totally on others          | 0         | 0    | 1           | 0.6  | 4               | 2.2  | 1             | 0.6 |                        |         |

|                                    |    |      |    |      |    |      |   |     |               |        |
|------------------------------------|----|------|----|------|----|------|---|-----|---------------|--------|
| <b>Wearing clothes &amp; shoes</b> |    |      |    |      |    |      |   |     |               |        |
| Depend on himself                  | 17 | 9.4  | 13 | 7.2  | 17 | 9.4  | 4 | 2.2 | $\chi^2=9.33$ | 0.156  |
| Need partial help                  | 18 | 10.0 | 41 | 22.8 | 53 | 29.4 | 6 | 3.3 |               |        |
| Depend totally on others           | 1  | 0.6  | 4  | 2.2  | 5  | 2.8  | 1 | 0.6 |               |        |
| <b>Urination &amp; Defecation</b>  |    |      |    |      |    |      |   |     |               |        |
| Depend on himself                  | 18 | 10.0 | 12 | 6.7  | 21 | 11.7 | 4 | 2.2 | $\chi^2=13.0$ | 0.043* |
| Need partial help                  | 18 | 10.0 | 45 | 25.0 | 50 | 27.8 | 6 | 3.3 |               |        |
| Depend totally on others           | 0  | 0    | 1  | 0.6  | 4  | 2.2  | 1 | 0.6 |               |        |

$\chi^2$  Kruskal-Wallis tests

\*significant at  $p < 0.05$

Z Mann-Whitney test

## DISCUSSION

Family caregivers of children with mental retardation experiences high level of emotional, financial and physical stress. There are multiple problems of having a mentally retarded child in the family. The problems are mainly related to the social ridicule and social stigma. Feelings of depression are common, particularly when realization of the child's retardation is recent. Mothers of children with mental retardation have the higher the perception of economic situation and income adequacy, parenting social support, and religious practices, and the lower the symptoms of depression and found that minority mothers showed the higher the religious coping, the lower the symptoms of depression (Sridevi, 2014). So, this study was carried out to explore burden of family caregivers for the children with mental retardation at Port Said city.

The results of the current study clarified burden experienced by the caregivers of mental retarded children, regarding daily activities of mental retarded children it was revealed that more than half of the studied mentally retarded children were able to eat and drink by themselves, bathing by themselves, had always slept alone, were depended on themselves on brush teeth and comb hair and were depended on themselves on urination and defecation. While, more than half of them were need partial help on wearing clothes and shoes .

This finding is similar with a study by Oh, Lee, (2019) titled "Caregiver Burden and Social Support among Mothers Raising Children with Developmental Disabilities in South Korea" who indicated that about half of mentally retarded children were able to be dependent on themselves at their daily activities because they were become more familiars with their health condition. On the contrast, Maheswari, K. (2014) in a study conducted titled " Burden of the Care Givers of Mentally Retarded Children " and founded that a round half of the studied mentally retarded children were on their care givers in most of their physical activities because of the majority of the studied mentally children were disabled and their disability was from the birth. In addition, Sridevi ,(2014) in his study titled" Care

Giver's Burden and Perceived Social Support in Mothers of Children with Mental Retardation in India " in their study stated that mothers have difficulty on childcare taking, difficulty of feeding, bathing and dressing and care taking time which their children not able to perform them alone.

Also, a study conducted by Oh, Lee, (2019) in his study titled " Caregiver Burden and Social Support among Mothers Raising Children with Developmental Disabilities in South Korea" discussed that substantial functional limitations in major life activity, such as self-care, language, learning, mobility, and capacity for Caregiver Burden and Social Support independent living . This may be due half of the family caregivers are educated .

Concerning psychological burden on mentally retarded children caregivers, the findings of the present study revealed that the largest percentage of the studied family care givers reported that having psychological burden sometimes at all aspects as: feeling stressed between caring for their relative and trying to meet other responsibilities for their family or work, feeling anger when they were around their relative, afraid what the future holds for their relative, feel strained when they were around their relative, feeling had losing of control of their life since their relative's illness and feeling uncertain about what to do about their relative.

Similarly, Maheswari (2014) listed that more than 44% of care givers of mentally retarded children in his study experience high level of psychological burden in taking care of the mentally retarded children and burden was experienced on various aspects as spend most of their time in care taking of special children and also look after other family members without psychological support from surrounding's family members.

Additionally, Shabo (2011) on a study titled " Psychosocial Impacts of Mentally Retarded Children on Parents in Sudan" to explore the psychological and social impacts of the mentally retarded child on his/her parents stated that the parents reported different psychological effects when they realized the children's disability and showed that most parents suffered from degrees of anxiety and depression ranging mainly from severe to moderate and recommends the provision of rehabilitation services and training of children in schools and special institutes, besides supporting their families psychologically and socially to reduce their burden.

Un similarity with Gohel , Mukherjee , Choudhary (2011) in his study titled" Psychosocial impact on the parents of mentally retarded children in Anand District" who found in their study that 53% of the parents had positive impact in terms of patience,

tolerance, empathy, sensitivity, support and relationship. The bulk of evidence converged that living with a disabled child causes a great deal of problems both for the family as a system, its members separately and their interaction without causing any psychological problems among them. It May due to family caregivers spend most of their time in care taking of special children and also look after other family members and this require more additional time and effort to do that.

For economic burden, it was found that high percent of the studied caregivers said that they did not have enough money to take care for their relative in addition to the rest of high expenses.

Likely, Ashrafi-Rizi, Najafi, Kazempour, Taheri (2015), showed that 48% of the respondents had borrowed money to meet out the household expenses and treatments. The respondents used to borrow money from their neighbors, relatives, and mortgage their jewels and some get money from the moneylenders for their urgent needs. Majority of the respondents are living in nuclear families and so it is difficult for them to get all sort of support from their in-laws.

In the same context , this result in an agreement with Frutos Marquez-Gonzalez et al , (2016).in a study titled "Prevalence of burden, family dysfunction and depression in primary caregiver of pediatric patients with disabilities at Mexico". who reported that 98% of mentally retarded care givers reported worsening economic situation without ability to rely their children needs. Also, in a study titled "Psychosocial Effect and Economic Burden on Parents of Children with mental Disability" Laskar et al, (2010 ) in a study titled " Psychosocial effect and economic burden on parents of children with mental disability at India" they discussed that their study revealed that the parents have to bear huge financial liabilities, over and above that of rearing of a normal child with increase mentally retarded children. This may be due to low economic status among most families and insufficient income to meet all demands for their mentally retarded children.

When measuring social burden at this study, it was found that the high percent of family care givers of mentally retarded children reported feeling that having social burden in caring their mentally retarded children regarding that their relative currently affects their relationships with other family members or friends in negative way, their social life had suffered because they were caring for their relative and feeling uncomfortable about having friends over because of their relative.

This finding agrees with the study conducted by Singh, Kumar, Sharma, Nehra (2014) in a study titled "Study of burden in parents of children with mental retardation" who reported that, in their present study parents in study group perceived high level of burden, impairment in social relationships and poorer perception of their environment. Furthermore, Ray (2018) stated that he found more than half of the studied intellectually retarded children especially mothers had high level of social burden and surrounding relationships. That's may be because of didn't having enough time for their social relation which their children need special care and there was a time for other leisure activity.

In regarding to physical burden of the studied mentally retarded children caregivers, the present study found that the high percent of them reported having physical burden sometimes in feeling that their health had suffered because of their involvement with their relative and burden feeling in caring for their relative.

Likely with Lasker et al., (2010) who reported that the mentally retarded children caregivers especially mothers suffered from high physical burden which the need special time and activities to their child without additional help from other family members. Also, Similarity with Frutos et al., (2016) in their study reported that the care of mentally retarded children require more physical exertion and high efforts which poses a physical burden to their caregivers.

In accordance with Recio, Molero, García-Ael, Pérez-Garín (2020) stated that family caregivers of children with mental retardation tend to report poor physical health at a higher rate than non-caregivers and have shown to experience physical strain from caregiving more often than those caring for adults. Further, family caregivers have frequently reported chronic fatigue and poor sleep as a result of stress associated with caregiving responsibilities. The reason for that may be because of the mentally retarded children need special care, time and physical effort than normal child in addition to, the other daily life demands and activity performed by them.

At this study, it was found that most of the studied caregivers said that they felt sometimes that their relative asked for their help than he/she needs, didn't have enough time for themselves, felt sometimes embarrassed over their relative's behavior, their relative was dependent on them, didn't have as much privacy as they would like because of their relative and felt disability to take care of their relative much longer. Although they said that, they sometimes felt that they should be doing more for their relative and doing better job in caring for their relative.

These findings are in agreement with Ray (2018) who stated that the parents of mentally retarded children had significant feeling of burden through their daily life but they accepted their important role toward their children. Likely, Recio, Molero, García-Ael, Pérez-Garín, (2020) discussed that there was a significant huge burden among the respondents regarding care provided to their intellectual disabled children at high level with strong negative impact on their lives. It may due to, there was a high load on caring mentally retarded children and there was a time that care giver felt that not able to provide mentally retarded children care, they satisfied and adapted regarding care of their children and become familiar with their role and responsibilities.

At this study, when measuring the level of burden among the studied caregivers by using evaluation burden scale, it was found that nearly half of them had moderate level of burden, less than one quarter of their had no burden, followed by more than one third of them had mild burden and minority of them had sever burden.

These results are in agreement with Singh, Kumar, Sharma , Nehra (2014) who showed that there was growing evidence suggested that care giving to these children leads burden to the caregivers that are the reason that prevailing stress or burden is reported by these individuals with a negative consequences among them. Also, these results were correlated with Turan Gürhopur, Dalgıç (2017) who said that all the participants were mothers and the mean score of the mothers in the family Burden Assessment Scale was ranged from quite to high level of burden which their children required requires more manpower, special health education and cost and time than healthy children. That's May be due to the studied caregivers faced different burden whether, physical, social, or economic and psychological with influence on their lives.

At this study , it was founded that, there was statistically significant relation between burden scale and family receiving economic support from government or non-government. On the same line with Kerenhappachu et al , (2014) who revealed that extra cost related to disabilities was the strongest predictor of increased caregiver burden and findings indicated that social support can reduce this burden.

Un likely with Singh , Indla & Indla (2018) who stated that there was no significant relation between financial status and burden level because various benefits and financial support given by the government. That means the level of economic burden would decrease with having any financial assistance to their children.

The present study illustrated that, there was statistical significant relation between burden scale and daily activities as eating, drinking, bathing, sleep alone, brush teeth & comb hair, wearing clothes & shoes and urination & defecation. It was found that moderate level of burden was reported at the high percent of them. The more the child relied on himself; the low burden level was found among caregivers. As well as Singh, Kumar, Sharma, Nehra, (2014) said that training of mental retarded child to be at least partial dependent on self-help in feeling less physical burden to caregivers.

The present study was showed that there was a statistically significant relation between level of burden and relative relation between father and mother of studied mental retarded children. That indicated to mental retardation can back to heredity and genetic factors. This in accordance with Clinical Genetic Service Department of Health (2012) that showed that some forms of mental retardation due to heredity and genetic causes.

## CONCLUSION

*Based on the findings of the present study, it can be concluded that:*

About tow fifth of the family caregivers(41.7%) had moderate level of burden. Care giving to mental retarded children leads to different burden to the family caregivers that are the reason that prevailing stress or burden is reported by these individuals. Understanding how to manage the negative consequences of caregiving is critical to developing and implementing realistic, appropriate response strategies.

## RECOMMENDATIONS

*Based on the results of the present study, the following recommendations were suggested:*

- 1) Increasing the public and society awareness about mental retardation through mass media and health education programs.
- 2) Design a session for family caregivers if possible to increase their orientation about mental retardation and decrease stress and feeling depression.
- 3) Increase knowledge about the welfare measures and rehabilitation measures to the public at regular intervals. This will helps the caregiver to provide better care and greater support to their children.

**Further studies must be carried out in order to:**

Designing training program to caregivers regarding coping and rehabilitation for their roles to their mentally retarded children.

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## عبء مقدمي الرعاية الأسرية لأطفالهم المتأخرين عقليا في مدينة بورسعيد

جهاد محمد أبو المعاطي<sup>1</sup>, نجلاء إبراهيم غيده<sup>2</sup>, ناهد عبدالعظيم عبدالسلام<sup>3</sup>, ايناس أحمد فرج عوض<sup>4</sup>

أستاذ تمريض صحة الأسرة والمجتمع بكلية التمريض - جامعة بورسعيد<sup>1</sup>, أستاذ مساعد تمريض صحة الأسرة والمجتمع بكلية التمريض - جامعة بورسعيد<sup>2</sup>, أستاذ مساعد تمريض صحة الأسرة والمجتمع بكلية التمريض - جامعة بورسعيد<sup>3</sup>

### الخلاصة

يحتاج الأطفال الذين يعانون من التأخر العقلي إلى رعاية خاصة من قبل الوالدين لتحسين مراحل نموهم مثل إجراء الفحوصات الطبية والاستشارة والتدريب. أفراد الأسرة هم أهم جزء للأطفال الذين يعانون من التأخر العقلي ليتمكنوا من عيش حياتهم بشكل جيد. لا شك أن التأخر العقلي هو إعاقة مدى الحياة وله تأثير كبير على حياة الأطفال وأسرهم. **الهدف:** تقييم عبء مقدمي الرعاية الأسرية لأطفالهم المتأخرين عقليا في مدينة بورسعيد. وتم استخدام تصميم بحث وصفي في مدارس التربية الفكرية للتأخر العقلي في مدينة بورسعيد ومدينة بورفؤاد. واشتملت هذه الدراسة علي أداتين تستخدمان لجمع البيانات المطلوبة من العينة؛ **الأداة (1)** استمارة استبيان منظم لمقدمي الرعاية لجمع البيانات المتعلقة بهما. **الأداة (2)** مقياس لتقييم عبء مقدم الرعاية. **النتائج:** كشفت الدراسة أن 41.6% من مقدمي الرعاية في الأسرة الذين شملتهم الدراسة يعانون من مستوى متوسط من العبء و32.2% من العينة يعانون من مستوى عبء بسيط و20% من العينة لا يعانون من اعباء و6.1% يعانون من عبء شديد. **الخلاصة:** يمكن الاستنتاج أن تقديم الرعاية لهؤلاء الأطفال يؤدي إلى عبء مختلف على عاتق مقدمي الرعاية الأسرية وهذا هو السبب في أن هؤلاء الأفراد يشعرون بالإجهاد. وفهم كيفية إدارة النتائج السلبية لتقديم الرعاية أمر بالغ الأهمية لتطوير وتنفيذ استراتيجيات استجابة واقعية ومناسبة. **التوصيات:** تصميم برنامج تدريبي لمقدمي الرعاية فيما يتعلق بالتأقلم والتأهيل للاهتمام بأطفالهم المتأخرين. يجب تقديم دعم مالي خاص لهذه العائلات لمساعدتهم على تلبية المطالب الإضافية وتكاليف رعاية أطفالهم المتأخرين عقليا.

**الكلمات المرشدة:** التأخر العقلي، مقدمي الرعاية الأسرية، العبء.