# Effect of Counseling on Patterns of Care, Stress and Life Burden on Parents of Mentally Retarded Children

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**Abstract:** Parenting a mentally retarded child is not an easy task. Parents having a mentally retarded child experience a variety of 'psychological stress' related to the child disability. Parents 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. Therefore, this study aimed at evaluating the effectiveness of counseling on patterns of care reducing stress and life burden on parents of mentally retarded children. A quasi-experimental research design has been utilized in this study. [From beginning of Feb 2013 until end of April 2013] .This study was conducted at the outpatient clinics in both: El-Abbaseya, Mental Health Hospital in Cairo and the Rehabilitation Center for Handicapped Children in Port-Said City. They recruited throughout a period of 3 months. The total sample was 52 parents (mothers / fathers) accompanying their mentally retarded children. The inclusion criteria were: mentally retarded child aged 1- 18 years, with sever level of IQ (20-40) of both sexes and family member living with the child at the same home. Data were collected through: 1)Socio-demographic data form, 2)A questionnaire [designed by the researchers] for assessment of basic knowledge about mental retardation,3) Observational checklist [was designed by the researchers] to record the parents' interaction patterns with their children before and after the counseling, 4)Questionnaire to elicit the parents approach in managing the different children problems before and after the counseling, 5)Caregiver Burden Scale and 6)Caregiver Stress and Depression. All the previously mentioned tools were applied before counseling sessions as a pre-test and after sessions as an evaluation test. Results showed, the effectiveness of the counseling sessions in providing knowledge and support to family caregivers, improving their behaviors and interactions toward their patients and alleviating their life burden. The ongoing development and evaluation of appropriate interventions for parents of mentally retarded children remain an important challenge to the mental health professionals. More research is needed in this area to determine the longer term effects of counseling.
[[Galila Shawky El-Ganzory; Gehad M.Abo El Matty and Mona AbdelRahman. **Effect of Counseling on Patterns of Care, Stress and Life Burden on Parents of Mentally Retarded Children.** *Life Sci J* 2013; 10(3): 1850-1858] (ISSN: 1097-8135). http://www.lifesciencesite.com**.** 276

**Key words:** Mental retardation, parents 'caregiver, burden, stress and counseling.

## 1. Introduction

Mental retardation is a state of developmental deficit, beginning in childhood, that results in insignificant limitation of intellect or cognition and poor adaptation to the demands of everyday life, intellectual disability is not a disease in and of itself, but is the developmental consequence of some pathogenic process(***World Health Organization, 2011)***.In the respect***,(Makimoto et al., 2011)*** added that the serious mental retardation in childhood, as an intelligence quotient below 50 with deficits in adaptive behavior, by contrast, defining mild mental retardation as an intelligence quotient in the range of 50-70 with deficits in adaptive behavior.

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 families ***(Abdel Malek, 2005)***.In a similar study***, (Clifford, 2007)*** found that the prevalence of mental retardation was 3.9% among an Egyptian population. According to the Central Authority for Public Mobilization and Statistics there are approximately two million persons with disabilities in Egypt, which represents about 3.5%in 2002 of total population. According to other statistics in 2000,the total number of disabled in Egypt is between 3.85-4.7 million and 73.3% of disabled persons in Egypt are mentally disabled(***Youth and Special Needs,2003*** and ***Johnson, 2007***).Most parents expect that their children will be attractive, smart, graceful, athletic, and loving .Parents of handicapped child not only mourn the loss of unfulfilled expectations but often face enormous strain on their psychological and economic resources. There is abundant evidence that parents of retarded children undergo more than the average amount of psychological stress. There is no universal parental reaction to the added psychological stress of raising a retarded child. A number of factors can influence reaction and adjustment, including the severity of the retardation. Family adaptation is also influenced by the parent's prior psychological make-up, availability and quality oh professional services, marital interaction, religious beliefs and the amount

of support the parents receive from friends, relatives and professionals, self –determination and intellectual functioning of the parents(***Mak&Kwok,2010*** and ***Karnataka, 2012).*** The presence of a child with mental retardation in the family creates additional needs, whether the family is able to meet the needs or not is dependent on number of factors like nature of the event, the family resources and its perceptions of the event. Unmet needs, tangible or intangible however create psychological stress (***Sartorius, &Schulze, 2005***).The presence of a child is a source of strain for the members of the family, particularly, for the parents. The interaction of a retarded child with his family is both more intense and more prolonged than if he /she was normal. As a result his/her parents need a great deal of help. The family's stability and its ability to handle problems can range from weak to strong.

Parent caregivers are identified as those who constantly need professional assistance and advice to raise their child, or even "curing" the problem once and for all, and these parents consider their children as having especial needs, rather than problems. Therefore, This study aimed at evaluating the effectiveness of counseling on patterns of care, stress and life burden on parents of mentally retarded children.

**Significance of the Study:**

One of the most difficult tasks facing the nurse as a counselor is that of counseling the parents of a mental retarded child. It is far more painful than counseling the parents of a dying child, for death is irrevocable and final and its wounds will often be healed with time. The diagnosis of mental retardation, on the other hand, often brings with it the specter of stress and burden for the parents and a life of disability for the child. Therefore, the nurse has an important role in helping parents to live with this problem so that they can cope with the crisis as they arise during the various stages of development of their retarded child. The nurse has also to motivate the parents of children with mental retardation to increase their knowledge and skills in dealing with their child. Thus, the nurse can provide the parents with the needed information and practices through nursing intervention designed to fulfill the aim of the study.

**Aims of the study:**

The aim of this study has four folds:

1. To assess the levels and types of patterns of Care of parents of mentally retarded children.
2. To assess the degree of stress and life burden on parents of mentally retarded children.
3. To design the counseling intervention for improving patterns of care, and reducing stress and life burden on parents of mentally retarded children.
4. To implement the counseling intervention for improving patterns of care, reducing stress and life burden on parents of mentally retarded children.
5. To evaluate the effectiveness of the counseling intervention for improving patterns of care, reducing stress and life burden on parents of mentally retarded children.

**2. Subjects and Methods**

**Research hypotheses:**

1-Parents of mentally retarded children will be stressed and have life burden.

2-Counseling session for parents of mentally retarded children will induce positive changes regarding stress and life burden and improve their patterns of care toward their children.

**Research Design:**

A one-group before - after Quasi-experimental design was used

**Setting:**

The study was carried out at the psychiatric outpatient clinics in both El-Abbaseya, Mental Health Hospital", affiliated to the Ministry of Health", and the "Rehabilitation Center for Handicapped Children" affiliated to Port Said City.

**Sample:**

The study subjects consisted of 52 parents (mothers / fathers), accompanying their mentally retarded children at outpatient clinics in both" El-Abbaseya, Mental Health Hospital" and the "Rehabilitation Center for Handicapped Children". They were recruited throughout a period of 3 months. [From beginning of Feb 2013 until end of April 2013}The sample was formed from the first consecutive parents who consented to participate in the study, according to two selection criteria: the mentally retarded children aged from 1 to 18 years with sever level of IQ (20-40) of both sexes and parent living with the child at the same home.

**Data collection tools:**

Six tools were used to measure the current study concepts:

1-Socio-demographic data form: that solicited information such as age, marital status, educational level, and work status.

2-A questionnaire designed by the researchers for assessment of basic knowledge about mental retardation. It covered eight areas that were: meaning and predisposing factors of mental retardation, signs and symptoms, methods of treatment, side effects of drugs, complications of the disease, degree of IQ and finally special needs of child with mental retardation. Parents answers were compared with a model key answer and accordingly their knowledge were

categorized into either: Unsatisfactory, less than 50% .Satisfactory, 50% or more.

3-An observational checklist was designed by the researchers to record the parents' interaction patterns with their children before and after the counseling, through physical contact, verbal contact and eye contact. Responses were evaluated by done or not done. As regards the scoring system for the observational checklist, a score of one was given to the mother for the task done correctly and a score of zero for the task done incorrectly or not done, and accordingly the mothers, total practices were categorized into :-

-Less than 50% were considered incorrect practices.

-50% and more were considered incorrect practices.

4-Aquestionnaire to elicit the parents approach in managing the different children problems before and after the counseling. It was developed by the researchers after reviewing the relevant literature.

The caregiver responded to 25 statements and his/her answers were marked as "Yes" or "No". A score of one was given for yes and a score of zero was given for one.

5- Caregiver Burden Scale: This scale was adapted from The Family Practice Handbook (http://www.fpnotebook.com). It is composed of 18 items to assess the caregiver burden symptoms. It addresses various aspects of caregiver burden symptoms including psychological, somatic, social and financial symptoms.

The answers to each item ranged from 1-3, where (1) refers to never, (2) refers to sometimes and (3) refers to always. The total score ranged from 18-54 points, and it was categorized into: Score from 18-<36 = mild; while score from 36-<54= moderate and 54 = severe.

This questionnaire was translated by the researchers into Arabic language and it was tested for its content validity by a group of five experts from the Psychiatric Medicine and Psychiatric Nursing staff. The required modifications were carried out accordingly. Then, test-retest reliability was applied and the tool proved to be strongly reliable (r=0.8222).

6- Caregiver stress and depression scale: It was developed by ***Radloff (1977).*** The CES-D scale was used to evaluate the stress and depression of caregivers which comprises 8 statements.

Scoring system: Each item was answered as "never"= 0, "rarely"= 1, "sometimes"= 2 and "always"= 3.

A total score ranged from 8-24, and summed. Caregiver stress and depression as follows: 8-<16 low stress, 16-<24 moderate stress, and 24 = high stress.

This scale was translated by the researchers into Arabic language. It was tested for its content validity by a group of five experts from the Psychiatric Medicine and Psychiatric Nursing staff. The required modifications were carried out accordingly. Then, test-retest reliability was applied and the tool proved to be strongly reliable (r=0.8).

**Pilot study:**

A pilot study was carried out on 10 parents being followed-up through their visits to the outpatient clinics in the two selected outpatient settings in both El-Abbaseya, Mental Health Hospital and the "Rehabilitation Center for Handicapped Children ", in order to test the clarity of the questions and applicability of the tools as well as to estimate the average time needed to fill in the sheets. Those who shared in the pilot study were excluded from the main study sample.

**Operational design:**

Implementation of the study included four phases. In the first phase (pre-assessment), ethical approval for conducting the study was obtained from the directors of the outpatients' clinics of the two selected settings, following verbal approval was obtained from participants who visited the outpatient clinics, during the data collection period. Nursing strategies used were questioning, brain storming, and group discussion, additionally, a poster was developed by the researchers, including illustrative pictures to facilitate explanation and encourage parents of mentally retarded children participation.

The researchers implemented the counseling intervention to parents during weekly sessions at specific days (Sundays, Mondays, &Wednesdays). Twenty six parents in each the center and the hospital were divided into 3 groups; each of them consists of five-six subjects. The researchers met each group one time per week for 60-90 minutes. The period of intervention was from 10-11 weeks for each group. So, the nursing intervention sessions were achieved within 3 months.

**Title of sessions.**

1st session: The researchers introduced themselves and briefly explained the study objectives to participants. Then, the participants proceeded to fill in the questionnaires under the supervision of the researchers. All information gathered was kept confidential. Analysis of the results of this phase determined the needs of parents of mentally retarded children.

2nd session: providing the women with necessary knowledge and information to build a sense of mastery and control, for improving their ability to meet their child's needs. Recognizing information, facts and concepts about child case. Decrease shock feelings by parents. The researchers respected their needs for expressing

their feelings more than confirmation that everything shall be OK.

3rd session: Modifying negative trends of parent towards their child which include: Detestation, terror, isolation, neglecting child emotional reactions, neglect or deprivation of child and cruelty.

4th session: Helping the parents in developing child case through child positive view through a network of strong relations to exchange experiences and information with families having similar cases. Increasing family and friends ties and granting them chance to recognize child case and its positive characteristics.

5 th session: Heading to the parents the places of services and social societies available in many places of governorates which enlighten family on how to deal with retarded children.

6 th session: Satisfying various child requirements through Need for interaction with others, need for independence from others, need to get information with scientific use and need for self-estimation.

7 th session: Setting detailed program for teaching daily life skills in view of child's mental level through training child on how to eat, dress, use toilet and bath by using group play with specialists capable of teaching them through play.

8 th session: Setting detailed program for teaching advanced skills in view of child's mental level through training on performing useful house work, participation in social activities, public transport, marketing, good handling in emergency and doing some vocational activity.

9 th session: The researchers cooperate with the Institute in urging the parents to attend congregational prayer and implant Islamic values and Islamic doctrine into them through religious contests, lectures and connect activities.

10 th session: The post intervention assessment was done by reapplying assessment of basic knowledge about mental retardation, 2) Parents' interaction patterns 3) Questionnaire to elicit the parents approach in managing the different problems 4) Caregiver Burden Scale 5) Caregiver Stress and Depression scale.

**3. Results**

Socio demographic data. The participants' age ranged from 20 to more than 50 years, with a mean age of 33.5±11 and less than three quarters of the caregivers were mothers, while fathers represented slightly more than quarter of them. As for the educational level of the participants, more than tenth were illiterate, a minority could just read and write or had primary education, slightly less than fifth finished the preparatory or secondary schooling, two fifths had university degree, and almost one fifth had post graduate degree. As for employment state of the parents, slightly more than half were unemployed and slightly less than half were employed. As regards marital status, more than two fifths were married, more than tenth were divorced, less than fifth were separated and less than third were widowed.

Concerning knowledge score among caregivers, table (1) reveals highly statistically significant improvements in the post nursing intervention results compared to pre intervention ($p$<0.001).

Regarding the comparison between the parents approach in managing the different children's problems before and after the counseling, Table (2) clarifies statistically significant improvements in post counseling intervention results compared to pre counseling intervention in all items of the questionnaire except for the items: "Identify nonverbal gestures or signals that your child may use to convey needs if verbal communication is absent", "Pick up signs of aggression before happened", and "Put side rails and headboard of your child with history of aggressive attack". There are no statistically significant differences in counseling post intervention results compared to pre counseling intervention for these items.

Considering comparison of the parents' interaction patterns with their children before and after counseling, table (3) clarifies statistically significant improvements in post counseling intervention results compared to pre counseling intervention in all items of the questionnaire.

As regard the comparison of the mean burden scale score among parents before and after counseling, table (4) clarifies that statistically significant improvements in nursing post intervention results compared to pre nursing intervention in all items of the scale

Regarding the comparison of the mean stress scale scores among parents before and after counseling, table (5) clarifies that statistically significant improvement in nursing post intervention results compared to pre nursing intervention in all items of the scale.

Table (6) presents the positive relationship between burden and stress of the parents with highly statistically significant correlation ($p$ <0.001)) i.e., when burden of the parents increased, stress of the parents increased also.

Table (7) displays the positive relationship between knowledge and burden and stress of the parents with highly statistically significant correlation ($p$ <0.001), i.e. when knowledge of the parents increased, stress and burden of the parents decreased..

**Table (1): Comparison of the knowledge score among parents before and after counseling.**

| Item | Pre | | | Post | | | $X^2$ | *P* |
|---|---|---|---|---|---|---|---|---|
| | Wrong | Incomplete | Right | Wrong | Incomplete | Right | | |
| Meaning of the disease | | | | | | | | |
| No | 31 | 18 | 3 | 17 | 23 | 12 | 33.48 | <0.001 |
| % | 39.6% | 34.6% | 5.8% | 32.7% | 44.2% | 23.1% | | |
| Degree of IQ | | | | | | | | |
| No | 37 | 11 | 4 | 21 | 18 | 13 | 44.07 | <0.001 |
| % | 71.2% | 21.2% | 7.7% | 40.4% | 34.6% | 25% | | |
| Predisposing factors | | | | | | | | |
| No | 21 | 29 | 2 | 10 | 17 | 25 | 36.28 | <0.001 |
| % | 40.4% | 55.8% | 3.8% | 19.2% | 32.7% | 48.1% | | |
| Signs and symptoms | | | | | | | | |
| No | 18 | 32 | 2 | 9 | 20 | 23 | 31.21 | <0.001 |
| % | 34.6% | 61.5% | 3.8% | 17.3% | 38.5% | 44.2% | | |
| Complications of the disease | | | | | | | | |
| No | 19 | 30 | 3 | 8 | 13 | 31 | 44.77 | <0.001 |
| % | 36.5% | 57.7% | 5.8% | 15.4% | 25.0% | 39.6% | | |
| Types of therapy | | | | | | | | |
| No | 18 | 31 | 3 | 9 | 11 | 32 | 44.84 | <0.001 |
| % | 34.6% | 59.6% | 5.8% | 17.3% | 21.2% | 61.5% | | |
| Side effects of each type of Therapy | | | | | | | | |
| No | 21 | 29 | 2 | 10 | 18 | 24 | 34.78 | <0.001 |
| % | 40.4% | 55.8% | 3.8% | 19.2% | 34.6% | 46.2% | | |
| Special needs of child with mental retardation | | | | | | | | |
| No | 23 | 27 | 2 | 11 | 14 | 27 | 45.10 | <0.001 |
| % | 44.2% | 51.9% | 3.8% | 21.2% | 26.9% | 51.9% | | |

**Table (2): Comparison between the parents' approach in managing the different children problems before and after the counseling**

| | Pre | | Post | | $X^2$ | *P* |
|---|---|---|---|---|---|---|
| | No | % | No | % | | |
| **Managing child with self care deficit.** | | | | | | |
| Call another family member for help. | 39 | 75 | 18 | 34.6 | 9.176 | <0.001 |
| Fulfill one aspect of your child self-care at a time | 11 | 21.2 | 38 | 73.1 | 5.140 | <0.001 |
| Provide simple, concrete explanations to identify aspects of self-care that may be within your child capabilities. | 18 | 34.6 | 45 | 86.5 | 4.282 | <0.001 |
| Encourage independence but intervene when your child is unable to perform | 9 | 17.3 | 31 | 59.6 | 7.373 | <0.001 |
| Use forcing approach. | 41 | 78.8 | 14 | 26.9 | 37.868 | <0.001 |
| **Managing risk for injury**. | | | | | | |
| Remove sharp object that your child uses out of reach. | 22 | 20.6 | 48 | 44.9 | 3.178 | <0.05 |
| Put side rails and headboard of your child with history of aggressive attack. | 11 | 10.3 | 48 | 44.9 | 1.163 | >0.05 |
| Pick up signs of aggression before happened. | 7 | 6.5 | 41 | 38.3 | 2.170 | >0.05 |
| Give tranquilizers without doctor ordered. | 33 | 30.8 | 18 | 16.8 | 15.850 | <0.001 |
| Stay with your child when he is agitated. | 22 | 20.6 | 48 | 44.9 | 3.178 | <0.05 |
| **Managing imbalanced diet.** | | | | | | |
| Give high protein and calories. | 19 | 17.8 | 45 | 42.1 | 4.657 | <0.001 |
| Provide favorite foods. | 11 | 10.3 | 38 | 35.5 | 5.140 | <0.001 |
| Sit with the patients during meal time. | 17 | 15.9 | 41 | 38.3 | 6.776 | <0.001 |
| **Managing impaired verbal communication.`** | | | | | | |
| Give reward for appropriate behavior. | 17 | 15.9 | 39 | 36.4 | 8.419 | <0.001 |
| Aversive reinforcement for inappropriate behaviors. | 41 | 38.3 | 19 | 17.8 | 8.033 | <0.001 |
| Learn your child by systematic habit training. | 6 | 5.6 | 29 | 27.1 | 5.379 | <0.001 |
| Identify nonverbal gestures or signals that your child may use to convey needs if verbal communication is absent. | 15 | 14 | 48 | 44.9 | 1.757 | >0.05 |
| Consult the doctor. | 17 | 15.9 | 42 | 39.3 | 6.014 | <0.001 |
| **Managing speech deficiencies**. | | | | | | |
| Remain with your child during initial interaction with members outside your family. | 17 | 15.9 | 46 | 43 | 3.294 | <0.001 |
| Explain to others the meaning behind the child nonverbal gestures and signals. | 20 | 18.7 | 42 | 39.3 | 7.738 | <0.001 |
| Use simple languages to explain to your child which behavior are acceptable. | 15 | 14 | 41 | 38.3 | 5.656 | <0.001 |
| **Managing sleep disorder.** | | | | | | |
| Increase medication dose at night. | 39 | 75 | 17 | 15.9 | 24.267 | <0.001 |
| Using forcing approach. | 41 | 78.8 | 21 | 40.4 | 34.413 | <0.001 |
| Consult the doctor. | 11 | 10.3 | 39 | 75 | 3.743 | <0.05 |

**Table (3): Comparison of the parents' interaction patterns with their children before and after the counseling**

| Interaction Patterns | Pre counseling | | post counseling | | $X^2$ | *p* |
|---|---|---|---|---|---|---|
| | No | % | No | % | | |
| Family interactional patterns. Attacking | 48 | 92.3 | 17 | 32.7 | 8.677 | <0.001 |
| Avoiding | 49 | 94.2 | 21 | 40.4 | 7.714 | <0.001 |
| Tolerant | 9 | 17.3 | 42 | 80.8 | 9.412 | <0.001 |
| Rigid | 47 | 90.4 | 15 | 28.8 | 9.033 | <0.001 |
| Belittling | 50 | 96.2 | 16 | 30.8 | 9.815 | <0.001 |
| Flexible | 9 | 17.3 | 43 | 82.7 | 9.815 | <0.001 |
| Judgmental | 51 | 98.1 | 16 | 30.8 | 10.247 | <0.001 |
| Expressions of caring | 10 | 19.2 | 41 | 78.8 | 8.677 | <0.001 |
| Embarrassing social behaviors | 46 | 88.5 | 21 | 40.4 | 6.872 | <0.001 |

**Table(4) : Comparison of the mean burden scale score among parents before and after counseling.**

| Burden Scale | Pre counseling | | Post counseling | | T- test | *p*-value |
|---|---|---|---|---|---|---|
| | Mean | ±SD | Mean | ±SD | | |
| I am over-taxed by my responsibilities | 2.5577 | .60758 | 2.0000 | .86319 | 8.019 | <0.001 |
| I have lost control over my life. | 2.6154 | .52966 | 1.7115 | .80041 | 10.816 | <0.001 |
| I should do more to help my child . | 2.1923 | .79307 | 2.1346 | .81719 | 1.767 | <0.05 |
| I feel burdened by caring for my child | 2.7885 | .53638 | 1.8077 | .95051 | 7.704 | <0.001 |
| My child needs help all the time. | 2.4615 | .72657 | 1.8654 | .88625 | 7.134 | <0.001 |
| My child depends on me to help him/her complete daily tasks. | 2.4615 | .72657 | 1.6923 | .85264 | 7.886 | <0.001 |
| I fear what may happen to my child in the future. | 2.6731 | .58481 | 1.9423 | .93753 | 6.845 | <0.001 |
| I fear that will not be enough money to care for my child | 2.3846 | .77089 | 2.0385 | .88476 | 5.196 | <0.001 |
| I fear I will not be able to continue to care for my child. | 2.7692 | .54648 | 1.7692 | .94174 | 7.946 | <0.001 |
| I wish someone else would take over my care giving responsibilities | 2.5577 | .60758 | 2.0577 | .87253 | 7.141 | <0.001 |
| I feel a sense of strain when I'm with my child | 2.7885 | .53638 | 1.7115 | .93592 | 8.390 | <0.001 |
| I sometimes feel anger toward my child | 2.0962 | .89134 | 1.3077 | .64286 | 7.103 | <0.001 |
| I am sometimes embarrassed by my child | 2.7885 | .53638 | 1.5385 | .87361 | 9.963 | <0.001 |
| I feel uncomfortable about having friends over. | 2.3846 | .77089 | 1.7308 | .86581 | 7.217 | <0.001 |
| Caring for my loved one has a negative impact on my social life. | 2.6923 | .64286 | 2.2692 | .90997 | 4.574 | <0.001 |
| Care giving has a negative impact on my relationships with other family members and friends | 2.6731 | .58481 | 1.7885 | .91473 | 7.893 | <0.001 |
| Care giving has affected my health. | 2.7500 | .55572 | 1.7692 | .94174 | 7.890 | <0.001 |
| Being a caregiver impacts my privacy. | 2.7500 | .55572 | 1.7500 | .92620 | 8.142 | <0.001 |

**Table(5): Comparison of the mean stress scale score among parents before and after counseling.**

| Stress Scale | Pre counseling | | Post counseling | | $X^2$ | *p* |
|---|---|---|---|---|---|---|
| | Mean | ±SD | Mean | ±SD | | |
| Do you feel that because of the time you spend with your child, you don't have enough time for yourself ? | 1.5962 | .69338 | .5192 | .64140 | 16.719 | <0.001 |
| Do you feel stressed between caring for your child and trying to meet other responsibilities (work/family)? | 1.3462 | .83747 | 1.2500 | .81349 | 80.889 | <0.001 |
| Do you feel strained when you are around your child? | 1.7692 | .42544 | 1.3654 | .81719 | 46.879 | <0.001 |
| Do you feel uncertain about what to do about your child? | 1.6346 | .56112 | 1.3654 | .81719 | 42.275 | <0.001 |

**Table (6): Correlation between burden scale and stress scale**

| **Item** | **Stress Scale** | |
|---|---|---|
| | **r** | ***P*-value** |
| **Burden** | **.781** | **<0.001** |

**Table (7): Correlation between total knowledge of the parents and burden and stress scale**

| Items | Total Knowledge | |
|---|---|---|
| | r | *P*-value |
| Burden | .725 | <0.001 |
| Stress | .937 | <0.001 |

## 4. Discussion.

Mental retardation refers to a complex socio-cultural phenomenon characterized by difficulty in complying with cultural values regarding intellectual and social behaviors. Retarded persons tend to violate such cherished cultural values of Arab society as intelligence, emotional independence, economic self-sufficiency, and physical attractiveness. As a result they have traditionally been rejected, isolated, stigmatized, and deprived of society's resources. Until quite recently, having a retarded child was generally considered to be a source of shame and indicative of serious deficiencies in one or both parents. Lack of understanding of the causes of retardation has further contributed to social exclusion and to general tendency to deal with mental retardation through denial.

Concerning the socio demographic characteristics, the finding of the present study revealed that less than three quarters of the caregivers were mothers, while fathers represented slightly more than quarter of them. This findings agreed with ***Awadalla, et al.(2010)*** who stated that mothers in the family usually has the responsibility of giving care for their children with mental retardation. Additionally, they feel guilty and blame themselves about their child case.

The mean age of the parents was 33.5±11 and their age ranged between 20-50 years. This finding is in agreement with ***Seltzer.et al. (2011),*** who emphasized that most of parents' age ranged between 25-50 years. However, this finding disagreed with ***Shibre.et al.(2011),*** who reported that the majority of parents aged 35-65 years.

Regarding the educational level of parents, the results clarified that almost two fifths had university degree and slightly more than one fifth had post graduate degree. This finding is on line with ***Scorgie and Sobsey(2008)***,who found out in their study that the educational level of parents was around two fifths having university degree, On the other hand, these findings are incongruent with ***Schulze and Angermeyer (2009),*** who stated in their study that parents had low educational level.

Regarding the employment status of the parents' the results clarified that more than half were unemployed and less than half were employed. This finding disagreed with ***Tossebro (2003),*** who found that more than 80% of parents were working.

The results of the current study showed that, there was a highly statistically significant difference of the parents' knowledge post counseling, this could be due to using different methods of counseling as face to face interaction. Lap top, discussion and demonstration supported by using real objects, posters, models, and handouts which are effective approaches for conveying information. In congruence with these results Mak***, and Cheung(2008),and Mak and Kwok(2010),*** who stated that counseling program can increase parents' level of information through the use of basic principles, which are acceptance, understanding, respecting parents' feeling, empathy, and communication and helping parents to make decisions for themselves according to their information and problems.

Concerning the comparison between the parents' approach in managing their children's problems before and after counseling, statistically significant improvements were detected post counseling intervention compared to pre counseling, which may be due to that the parents typically review the problems several times to enhance understanding, come up with a variety of probable solutions, work harder to manage the situation, and analyze the problem bit by bit and seek assistance from others. This also may be attributed to that the majority of parents were either university or post graduate level of education, which helped them to gain information from different sources as books, journals, and internet. Moreover, education helps them increase their ability to access community resources and interact effectively with the health care team. These results are supported by the study of ***Clifford, (2007),*** who explained that parents who receive instructions about the problems of their children are more comfortable to manage their children at their home. As well, ***Sartorius and Schulze(2005);***and ***Kirby(2006),***identified also that the educated parents are more powerful and more oriented about their child problems.

This study revealed also that no statistically significant difference in counseling post intervention results compared to pre counseling intervention in relation to "Identify nonverbal gestures or signals that your child may use to convey needs if verbal communication is absent". "Pick up signs of aggression before happened" and "put side rails and headboard of your child with history of aggressive attack". It may be due to that these three items need adequate assistance from the mental health professionals and this practice must be mastered by training and from their point of view they considered these items are not their responsibility but are the doctors' responsibility. These results are supported with those of ***Pollio, et al. (2011),*** who suggested that family members

who do not understand relatives' behaviors, such as hostility, apathy, and social withdrawal, falsely attribute these behaviors to negative aspects and react more negatively.

The result of the present study showed post intervention improvement of the parents' behavior with their children, as well as their interaction toward them. It may be due to that the information provided to parents during counseling succeeded in preparing them to follow more proper patterns in dealing with the different interaction, and with the different child behavior. Additionally, they cooperates with the Institute in urging the parents to attend congregational prayer and implant Islamic values and Islamic doctrine into them through religious contests, lectures and connect activities to increase their religious attitude toward their children and to overcome their stigma toward their children.

This could be also due to the fact that the working parents especially mothers have a good chance and good plenty of time to care for their children's behavior by themselves and also they are in need for any valuable instructions related to their children's behavior. This was emphasized by ***Narmada,(2010)***, who mentioned educated mothers is usually associated with good interaction toward their children's behavior.

The finding of this study revealed statistically significant improvement post counseling intervention compared to pre counseling in all items of burden and stress scale. This may be considered as an ultimate sequence of the counseling program. Additionally, these results might be attributed to the strong desire of the participants to receive the needed information about their children's illness, also the lack of caregiver skills to handle patient problems, allowing more interaction between each others and sharing experiences, in addition to giving chances to express their held feeling related to care giving duties and burdens. This finding is in line with ***Stuart, et al. (2008),*** who clarified that education is probably therapeutic because it reduces burden and stress and increases parent empowerment.

This result revealed the positive relationship between burden and stress of the parents with highly statistically significant improvement. This finding is on line with ***Kirgiss(2008),and Paskiewicz,(2009),***who stated that burden is a state of emotional, mental and physical exhaustion caused by excessive and prolonged stress, occurred when the parents felt overwhelmed and unable to meet constant demands.

This result revealed the positive relationship between knowledge and burden and stress of the parents with highly statistically significant improvement. This positive relation may be attributed to the fact that such barriers can be prevented to reduce the burden such as; poor disease education and poor health services infrastructure as well as delay in obtaining help about how to deal with the child problems. This finding agreed with another study, carried out by ***Gorden,et al.(2012),***which stated that better understanding of the nature of illness and how to manage can improve psychological state and decrease stress which finally improve their burden.

**Conclusion**

In conclusion, one can say the mental that illness in the home can affect not only life burden on parents of mentally retarded children but also the health of the family members, a stress emotional climate, anxieties and practical burdens.

The caregiver is a dynamic process which includes patient and a person who is involved in long term care of the patient. This long term care very often leads to experience burden in the caregiver ,thus this lack in the care giver support and equivocal success, with intervention aimed at alleviating the caregiver burden through counseling.

**Recommendations**

Based on the results of the present study, and hypotheses, it is recommended that:

-Continuous health education and counseling programs are necessary to improve parents coping patterns toward care of their mentally retarded children through:

• Discussing child problems and needs.

• Applying guidance including information about community resources, and comprehensive coping care needs as physical, social, emotional, motor, and communication skills to be provided for children with mental retardation in order to meet their needs and prevent further complications.

• Reassuring the importance of follow up care.

-Counseling should be multi-staged (at birth, and at least again at age two, at school entry, prior to and during pubertal changes, and yearly during adolescence) as well as examining parental coping strategies at different stages of development would be an interesting avenue for future research.

-Adopt nursing interventions that suit the individual educational needs of mentally retarded children and their parents to help them in coping positively with mentally retardation and its management.

-Instructional pamphlet or guidelines should be made available at all inpatient, outpatient and health centers for parents about mentally retarded children.

-Further studies are needed to continue follow up for these children through activities, school health social services, and skills in collaboration with school and related centers.

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