

Burn-Out and Coping Patterns among
Family Members of Mentally
Retarded Child

Protocol

Submitted for partial fulfillment of the requirement
of Master Degree in Science of Nursing
(Psychiatric and Mental Health Nursing)

By

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• Introduction

Over the past two decades, family studies in mental retardation have changed from a negative to more balanced perspective or moved from a pathology perspective to stress coping perspective. (*Greenspan, et al, 1997*).

Mental retardation is described by American Association on Mental Retardation (AAMR) as the presence of subaverage general intellectual functioning associated with or resulting in impairment in adaptive behaviour, and manifested during the developmental period. An intelligence quotient (I.Q.) scale less than 70. (*Boyd, 2002*).

The prevalence of mental retardation has been estimated at 20%, with a range from 1% to 2.5% of population. Nearly 90% of those mentally retarded children are in the mildly retarded. (*Boyd, 2002*). Community-based studies found prevalence rates of 30% to 40% for co-existent psychiatric disorders in children with mental retardation. (*Gelder, et al, 2001*).

In Egypt there are more than 3.4 millions mental retarded child with different degree of retardation of population, only 1% received a health care. (*El Sherif, 1997*).

Families who have a mentally retarded child had to spend their life as a care givers specially the mentally retarded child exhibit a significant limitation in at least two of the following skill areas : -
communication, self-care, home living, social / interpersonal skills, use of community resources, self-direction, work, leisure, health, and safety. (*Shives and Isaacs, 2000*).

Also the mentally retarded child has a risk for prolonged list of disorders such as physical disorders (sensory and motor disabilities, epilepsy and incontinence), or psychiatric disorders (schizophrenia, mood disorder, anxiety disorders, eating and sleeping disorders). (*Cowen, et al, 2001*).

أحمد محمد صالح
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These families were perceived to be families in a crisis, they may suffer from more divorces, and parent and siblings are severely depressed. These families may have more difficulty when there is only one parent, when the mother received a little support from her husband; or when the family is of low socio-economic status. *(Kaplan and Sadock's, 2000)*.

The diagnosis of mental retardation is not made until after the first year of the child life, the parent are too grive for the intact child they had hoped and planned for, they have significantly mourn for unhealthy child much as they would mourn for a dead child. They experienced prolonged depression, guilt, sham, or anger, and burn-out feeling which manifested in physical and emotional fatigue, a sense of total futility, dissatisfaction with the life, apathy and suspicion. A few reject their child others become over involved in their care. *(Gelder, et al, 2001)*.

So families with mentally retarded child must be prepared to deal with their children through effective coping patterns which may include two kinds: problem-solving patterns, which can be used to make adverse circumstances less stressful, and emotion-reducing patterns, which alternate the response to the stressors. *(Cowen, et al, 2001)*.

• Significance of the study

When the child is found to be mentally retarded the family's members had to make great changes in their arrangement and expectation for their child, also they had to change their life style for meeting the mentally retarded child's need. They may have difficulty in coping with this crisis, and even they adjusted psychologically well they still faced with prolonged hard work, frustration, social and financial problems. These families faced with a life-time of care giving responsibilities and challenges, this study will investigate changes over time in their burn-out or mourn feelings, how these families cope with this crisis, and the effect of coping patterns on the family's well being.

• Aim of the study

- This study will be conducted to
 - 1- Assess burn-out feelings of families who have mental retarded children.
 - 2- Evaluate their coping patterns.

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- **Research questions**

The problems of study lies in the following questions:

1. How will these families face the care giver responsibilities ?
2. What changes could be occur over time in their burn-out feeling?
3. How these families will cope with this crisis ?
4. What is the effect of coping patterns on the family's well-being?

- **Subject and Methods**

- 1- Setting

This study will be conducted at the pediatric out patient clinic of Psychiatric Institute at Ain Shams University, and at the El Abbassiya Psychiatric Hospital.

- 2- Sample

The sample of this study will be composed of all available number of family's members accompanying with their mentally retarded children at the psychiatric out-patient clinic, through six months (three days per week).

- **Criteria of the sample.**

For the mentally retarded child.

1. An intelligence quotient (I.Q.) scale less than 70 degree.
2. Sample age from 1 year to 18 year old.

For the family's member.

1. Parent and sibling who are lived with mental retarded child at the same home.
2. Family's member who taking the responsibilities as care givers for this child.

- **Tools of data collection : -**

- 1- Interviewing questionnaire which composed of :

- i) Questionnaire to collect data about demographic characteristics of study samples.

- 2- Using two types of psychometry scales:

- i) Burn-out rating scale (Jalowiec, 1984): to evaluate the burn-out feeling on the family member as a care giver for mentally retarded child (Maslach, 1986).
- ii) Coping rating scale to evaluate the coping patterns for these families.

Fatma Mahmoud M. El Solh - M.A. , Ph.D

- Results : -

Results of the study will be tabulated and discussed.

- Discussion.

- Conclusion.

- Recommendation.

- Summary.

- References.

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الاحتراق النفسي و أنماط التكيف لدي
أفراد أسرة الطفل ذو الاحتياجات
الخاصة "الإعاقة الذهنية"

رسالة

تواظنه للحصول علي درجة الماجستير
في التمريض النفسي

مقدمه من

عبير محمد الشحات علي
أخصائية تمريض بالمعهد الفني الصحي بامبابية

المشرفون

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المقدمة:

خلال القرنين الماضيين انتقلت الدراسات الأسرية في مجال الإعاقة الذهنية من النظرة السلبية إلى النظرة الإيجابية، أي من التركيز على كيفية حدوث المرض إلى طرق التكيف مع هذا المرض بالنسبة للأسرة.

عرف التخلف العقلي بواسطة منظمة الصحة الأمريكية على أنه "وجود انخفاض في معدل ذكاء الطفل أقل من الحد الأدنى، ينتج عنه قصور في الوظائف الحيوية وسلوكيات الطفل، وتظهر أعراضه خلال فترة النمو والتطور ويكون معدل الذكاء أقل من ٧٠ درجة.

تصل نسبة الإعاقة الذهنية نحو ١% : ٢,٥% من نسبة سكان العالم، حوالي ٩٠% من هذه الإعاقة يتم أدرجها تحت نوع التخلف العقلي البسيط. الدراسات الاجتماعية التي أجريت أثبتت أن حوالي ٣٠% : ٤٠% من الأطفال المصابين بالإعاقة الذهنية يعانون بالفعل من اضطرابات نفسية وعضوية أخرى.

تبعاً للمركز القومي للتعينة العامة والإحصاء فإن عدد المعاقين ذهنياً في مصر قد يصل إلى ٣,٤ مليون نسمة بمختلف أنواعه ودرجاته، وحوالي ١% من هؤلاء المصابين هم الذين يتلقون الرعاية الصحية اللازمة.

لا يتم اكتشاف الإعاقة الذهنية إلا بعد العام الأول من عمر الطفل، وعندها يعاني الأبوين من الاكتئاب الحاد، الإحساس بالذنب والخجل، الغضب وقد يصل بهم الأمر إلى درجة من الاحتراق والإنهاك النفسي الذي يظهر في صورة إجهاد نفسي وعصبي، إجهاد عضوي، إحباط على المستوى الشخصي أو الاجتماعي، تبدل في المشاعر وخلافه القليل من هذه الأسر يرفضون أطفالهم والغالبية ينغمسون أكثر في الرعاية بأطفالهم.

الأسر التي لديها طفل معاق ذهنياً يحملون عبئاً إضافياً، وخاصة أن هذا الطفل لديه علي الأقل قصوراً شديداً في أكثر من مجال مثل التواصل مع الآخرين، الاهتمام بالنظافة الشخصية، المهارات الاجتماعية والشخصية، استخدام الخدمات التي يوفرها المجتمع، توجيه النفس، العمل وخلافه. كما أنهم أكثر عرضة من الأطفال الأصحاء للإصابة بالاضطرابات النفسية مثل (الفصام، القلق المرضي، اضطرابات النوم والأكل) وأيضاً اضطرابات عضوية مثل (الاضطرابات الإدراكية والاضطرابات الحركية والصرع).

عندما تكتشف الأسرة أن الطفل معاق ذهنياً تضطر إلى عمل تغيير جذري في نظام حياتها وأولوياتها، لتلبي احتياجات هذا الطفل إلا إنها قد تجد صعوبة في التكيف مع هذه الكارثة نظراً للعمل الشاق الموجه للرعاية بهذا الطفل، إلى جانب الإحباط والمشاكل المادية والاجتماعية التي تواجه الأسرة. لذلك فهذه الدراسة تبحث عن أثر الاحتراق النفسي على الأسرة وأنماط التكيف لدى هذه الأسرة.

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ذو الاحتياجات الخاصة "الاعاقه الذهنية"

رسالة مقدمة

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لظفي

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