

Impact of Mentally Retarded Child Upon Parents

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In this study which was designed to allow a detailed investigation of parents of mentally retarded children (MRC), in comparison to parents of physically disabled children (PDC) and parents of normal children (NC), in a trial to throw light on the impact of MRC on their parents, each of three compatible groups was divided into high and low socioeconomic subgroups.

All groups were asked for frequent interviews, during which a full details about the study was explained and during which also the parents were given the chance to express their positive and negative feelings and attitudes towards their handicapped children. All parents consented to participate in the study. A semistructured interview was performed by all available parents from which important demographic data were obtained and discussed. Three questionnaires were also performed: I. Parenting Stress Index. II. Symptom Checklist 90. III. Attitudes Towards Handicapped Questionnaire. Wechsler I.Q. test was applied for all children. Psychiatric as well as physical examination of all parents were also done. Results proved significant prevalence of positive consanguinity among parents of MRC and parents of NC. Parents of MRC experienced higher level of stress which was not affected by the difference in socioeconomic levels. Stress was more among parents of female cases and also more in cases of lower I.Q. Parents of MRC were found to be more prone to psychiatric disorders especially anxiety, depression and panic disorders. Positive attitudes towards MRC were found among their parents. Parents of MRC expressed many concerns about fear from next pregnancy, fear of their death, impact on siblings, onset of puberty, and availability of community services. Suitable recommendations were concluded.

(Egypt. J. Psychiat., 1998, 21 :171 - 183).

INTRODUCTION

Mental retardation has a great impact on the family. Having a child who will remain a mental cripple for his entire life places parents in a great conflict. It is the failure to resolve their conflicts

that often results in chronic bitterness, resentment or apathy (Stubblefield 1977).

Although some parents of mentally retarded children have been described as defensive, depressed overprotective, denying, guilt ridden, rejecting, the majority are well adjusted (Szymanski & Crocker 1989).

Two empirical typologies of families with retarded children have emerged, both are based on analysis of the psychosocial environment of home. In the typology of families with trainable men-

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tally retarded children, five family types were discovered : cohesive, low - disclosure, disadvantaged, control oriented and child oriented. The typology of families with slow learning children had seven family types: child oriented (cohesive), low disclosure, disadvantaged, learning oriented, achievement oriented, expression oriented and outer directed (Mink et al 1983; Mink et al 1984; Mink & Nihira 1987).

Weisner et al (1991) described two types of families religious and non religious. They found that religious parents were somewhat more familistic than were non religious.

El - Guindy et al (1994), found that fathers were more accepting than mothers and more stable in their attitudes than mothers .

Willoughby and Glidden (1995), found that greater father participation in child care was related to high marital satisfaction for both parents. Higher family income was also related to higher marital satisfaction for fathers only.

Aim of the work

Determination of impact of mentally retarded child on their parents.

Comparison of this impact in high and low social standard parents.

Studying the impact of mentally retarded child on parents in comparison to physically disabled child as well as normal child.

Determination of variables associated with stress on parents of mentally retarded child such as : mothers versus fathers; social standard; consanguinity; sex of the mentally retarded; degree of retardation; parental age.

SUBJECTS AND METHODS

The samples of this study were se-

lected from different places according to inclusive as well as exclusive criteria . Parents of mentally retarded children (MRC) were asked for an interview through schools of MRC. Parents were divided into high and low social standard according to parental level of education, occupation and housing condition (Eshra and Shaheen, 1979).

Twenty high social standard parents of MRC who fulfilled our inclusive criteria (age above 5 years, I . Q. below 70 attending a mental retardation school program) were selected from private specialized schools of mentally retarded children . Another twenty low social standard parents of MRC who fulfilled the same inclusive criteria were selected from governmental specialized schools for MRC.

Presenting parents were asked for an interview , during which a full explanation of the aim of our work was introduced after which all parents in the study consented to participate.

Parents were given the chance to express their feelings toward their child and to tell us the whole experience they passed through having a mentally retarded positive feelings and felt supported by the therapist.

A semistructured interview was done to gather different demographic data such as the parent's age , paternal and maternal occupation, consanguinity , type of the family, socio-economic standard .

Three questionnaires were then performed by the available parents. These include : Parenting Stress Questionnaire, Symptom Checklist 90 and Attitudes Toward Handicapped Questionnaire .

A thorough clinical psychiatric examination was also performed for all presenting parents who were asked about any investigations done confirm-

ing their physical disorders and they were also asked about any treatment received whether medical or psychiatric.

Two other groups were taken for control, parents of physically disabled children (PDC) and parents of normal children (NC). Each of these two groups were divided into high and low social standard subgroups according to the same criteria of parents of MRC.

Twenty high social standard parents of PDC were selected from private hospitals and physiotherapy centers. Twenty low social standard parents of PDC were selected from out - patient clinic of Benha university hospital . The presenting parents were subjected to the same steps of parents of MRC , taking into consideration that these parents had no MRC.

Physical disabilities included neurological disorders as poliomyelitis, myopathy, infantile hemiplegia and orthopedic deformities such as talipes equinovarus.

Ten high social standard parents of normal child were selected from staff members of Benha university hospital . Ten low social standard parents of normal child were selected from workers in the same place.

These parents were also subjected to the same steps of parents of MRC and PDC.

All children in this study (MRC , PDC and NC) were subjected to :

I.Q. testing : to diagnose mental retardation and to exclude mental retardation from PDC and NC.

Demographic data including information from the parents about personal data, pregnancy , delivery, order of birth, trauma through the semistructured interview.

Thorough physical examination.

The psychometric tests used in this

study include the followings:

Parenting Stress Index . (El - Beblawy, 1988).

Symptom Check List 90 . (El - Behiry , 1984).

Attitudes Toward Handicapped Questionnaire (El - Quraity , 1992).

Wechsler I.Q. test . (Arabic version by Ismail and Melika, 1993).

RESULTS

Table 1
Comparison of Demographic Data Between Parents of the Three Studied Groups

Studied groups Parents Demographic Criteria	Parents of Mentally Retarded Child (N=41)		Parents of Physically Disabled Child (N=43)		Parents of Normal Child (N=22)	
	No	%	No	%	No	%
Type of family						
- Nuclear	32	78.1	37	86.1	18	81.8
- Extended	9	21.9	6	13.9	4	18.2
X ²						
P			0.915	>0.05	0.124	>0.05
Consanguinity						
- Negative	30	73.2	42	97.7	14	63.6
- Positive	11	26.8	1	2.3	8	36.4
X ²						
P			10.292	<0.05	0.618	>0.05
Family Size						
- Less or equal 5	29	68.3	21	48.8	15	68.2
- More than 5	12	31.7	22	51.2	7	31.8
X ²						
P			3.269	>0.05	0.076	>0.05
Sex of presenting parent						
- Male (father)	7	17.1	19	44.2	8	36.4
- Female (mother)	34	82.9	24	55.8	14	63.6
X ²						
P			7.219	<0.05	2.937	>0.05

Table 2
Results of Wechsler's I.Q Score of Children of the Three Studied Groups

Test of Significance	Studied groups		
	Mentally Retarded Children	Physically Disabled Children	Normal Children
-			
X	48.1	10.70	110.9
± SD	6.4	12.2	15.9
t		27.536	22.231
P		<0.01	<0.01

Table 3
Results of Parenting Stress Index Questionnaire Among the Three Studied Group

Test of Significance	Studied groups		
	Parents of Mentally Retarded Child	Parents of Physically Disabled Child	Parents of Normal Child
a- Child domain score:			
-			
X	19.122	61.163	48.864
± SD	18.530	19.695	25.239
T	-	4.300	5.399
P	-	<0.01	<0.01
b- Parent domain score:			
-			
X	58.902	56.837	44.545
± SD	22.486	20.538	20.054
t	-	0.440	2.506
P	-	>0.05	<0.05
c- Total score domain:			
-			
x	73.488	62.419	50.454
± SD	20.284	21.846	21.208
t	-	2.403	4.229
P	-	<0.05	<0.01

Table 4
Results of Parenting Stress Index Questionnaire in High and Low Social Standard Mothers of Mentally Retarded Child.

Studied groups Parenting Stress index	High social standard Mothers of Mentally Retarded Child (N=19)		Low Social Standard Mothers of Mentally Retarded Child (N=15)		t	P
	$\bar{X}$	$\pm$ SD	$\bar{X}$	$\pm$ SD		
Child Domain Score	80.316	19.779	74.667	17.368	0.872	> 0.05
Parent Domain Score	57.368	27.201	63.000	19.530	0.675	> 0.05
Total Score	73.105	23.043	72.600	19.160	0.068	> 0.05

Table 5
Results of Symptom Checklist 90 (S.C.L. 90) Questionnaire Among the Three Studied Groups.

Test of Significance	Studied groups		
	Parents of Mentally Retarded Child	Parents of Physically Disabled Child	Parents of Normal Child
a- Somatization score:			
$\bar{X}$	17.707	17.023	15.591
$\pm$ SD	13.534	9.405	7.082
t		0.270	0.683
p		>0.05	>0.05
b- Obsessive compulsive score:			
$\bar{X}$	12.098	11.186	12.273
$\pm$ SD	4.668	6.134	4.289
t		0.764	0.146
p		>0.05	>0.05
c- Interpersonal sensitivity score:			
$\bar{X}$	10.122	8.233	9.227
$\pm$ SD	5.330	5.103	4.577
t		1.660	0.666
p		>0.05	>0.05
d- depression score:			
$\bar{X}$	19.293	19.488	13.500
$\pm$ SD	8.159	11.825	3.067
t		0.088	3.201
p		>0.05	<0.05
e- Anxiety score:			
$\bar{X}$	10.122	11.558	6.818
$\pm$ SD	6.827	6.937	2.281
t		0.171	2.198
p		>0.05	<0.05

Table 6
Results of SCL 90 Questionnaire between Mothers
of Male and Female Mentally Retarded Child

Studied groups SCL 90 questionnaire	Mothers of Mentally Retarded Male (N = 21)		Mothers of Mentally Retarded Female (N = 13)		t	P
	$\bar{X}$	$\pm$ SD	$\bar{X}$	$\pm$ SD		
Somatization score	18.33	13.658	19.231	15.969	0.175	>0.05
Obsessive compulsive score	11.667	4.305	13.077	5.235	0.855	>0.05
Interpersonal sensitivity score	10.381	5.527	9.769	5.570	0.313	>0.05
Depression score	18.952	7.736	20.846	7.459	0.703	>0.05
Anxiety score	9.809	7.393	10.769	6.508	0.384	>0.05
Hostility score	3.000	1.949	4.769	2.920	2.124	>0.05
Phobic anxiety score	5.095	4.753	5.615	4.445	0.318	>0.05
Paranoid ideation score	4.952	3.801	5.077	3.861	0.092	>0.05
Psychoticism score	5.000	3.098	6.385	5.140	0.984	>0.05

Table 7 a
Results of Total Score of Attitudes Towards Handicapped
Questionnaire among Parents of the Three Studied Groups

Studied groups Test of Significance	Parents of Mentally Retarded Child	Parents of Physically Disabled Child	Parents of Normal Child
	$\bar{X}$	$\bar{X}$	$\bar{X}$
$\bar{X}$	155.17	147.05	145.83
$\pm$ SD	8.79	8.61	11.33
t	-	4.271	3.624
P	-	<0.01	<0.05

Table 7 : b
Results of Total Score of Attitudes Towards Handicapped Questionnaire between
high and Low Social Standard Mothers of Mentally Retarded Child

Studied groups Attitudes Towards Handi- capped	High social Standard Mothers of Mentally Retarded Child (N = 19)		Low Social Standard Mothers of Mentally Re- tarded Child (N = 15)		t	P
	$\bar{X}$	$\pm$ SD	$\bar{X}$	$\pm$ SD		
Total score	159.470	6.729	150.148	8.838	3.495	<0.05

Table 8
Correlation Coefficients (r) and Probability Value
(P) Between Different Parameters Among Parents of Mentally Retarded Child

Parameter	Attitudes Towards Handicapped Questionnaire (Total score)		SCL 90 Questionnaire Depression Score		SCL 90 Questionnaire Anxiety Score		Parenting Stress Index questionnaire (Total score)	
	r	P	r	P	r	P	r	P
Parent's age	0.213	>0.05	-0.075	>0.05	-0.155	>0.05	-0.028	>0.05
Consanguinity	-0.352	<0.05	0.231	>0.05	0.218	>0.05	-0.081	>0.05
Family type	-0.175	>0.05	-0.026	>0.05	-0.097	>0.05	-0.022	>0.05
Family size	-0.224	>0.05	-0.142	>0.05	-0.028	>0.05	-0.236	>0.05
I. Q.	0.066	>0.05	-0.096	>0.05	-0.027	>0.05	-0.388	<0.05
Order of Birth	-0.106	>0.05	-0.103	>0.05	-0.024	>0.05	-0.041	>0.05
Child's age	0.158	>0.05	0.048	>0.05	-0.128	>0.05	-0.106	>0.05

Table 9
Expression of Different Concerns During Interviewing Parents of Mentally
Retarded Child and Physically Disabled Child

Studied groups Concerning Matter	Parents of Mentally Retarded Child (N = 41)		Parents of Physically Disabled Child (N = 43)		Z	P
	No	%	No	%		
1- Expression of death fear	36	87.8	17	39.5	4.583	<0.01
2- Fear of next pregnancy	9	22.0	0	0.0	3.251	<0.05
3- Expression of worrying about siblings	11	26.8	5	11.6	1.774	>0.05
4- Availability of good community service and its impact.	31	75.6	4	9.3	6.162	<0.01
5- Onset of puberty as a stressor on parents	13	31.7	2	4.6	3.236	<0.05

DISCUSSION

The study was designed to allow a detailed investigations of parents of mentally retarded children (MRC) in comparison to parents of physically disabled children (PDC) and parents of normal children (NC), in a trial to through light on the impact of MRC on their parents, hoping that this might help in better planning for managing such families in the community.

Demographic data of parents of the three studied groups proved compatibility of the average ages. Positive consanguinity was found to be significantly prevailing among parents of MSC than parents of PDC (in 26.8% & 2.3% respectively) "table 1" an expected result that came in accordance with that of Zigler et al (1984) and Hadapp & Zigler (1986), who concluded that 50-80% of the variability in I.Q. is due to genetics and conversely, that from 20-50% is due to environment or gene - environment interactions.

In our study we found that positive consanguinity was also prevailing among parents of NC, a cultural aspect of marriage in Egypt that needs raising awareness about its hazards. "table 1".

There was a higher level of stress experienced by parents of MRC than those of PDC as well as of NC regarding "child domain" (X79.122, 61.163 & 48.864 respectively) and the difference was statistically significant ($P < 0.01$). "table 3" a result that came in accordance with that of Beckman (1983); Friedrich et al (1985); Minnes ((1988); Seltzer & Krauss (1989); Frey et al (1989); Beckman (1991); Orr et al (1991) and Dyson (1993).

It is interpreted that the child's risk-factors (behavioral and medical problems) relate strongly to parenting stress

and burden. The child's variables, both behavioral and medical problems were related to greater parent and family stress. Other characteristics of MRC such as their social responsiveness, temperament, repetitive behavioral patterns and additional or unusual care-taking demands were related to stress. Pessimism as regards child's future was found also to be related to stress.

The same results were found regarding the "parent domain score" on (Parenting Stress Index Questionnaire), "table 3", as well as the total score and the differences were statistically significant ($P < 0.05$).

Regarding results of "Parenting Stress Index Questionnaire" in high and low standard mothers of MRC "table 4" the results were insignificant along the child domain, parent domain and total score of stress ($P > 0.05$), results that came in accordance with that of Beckman (1983), Friedrich et al (1985), Donovan (1988), Flynt & Wood (1989) and Seltzer & Krauss (1989).

High social standard mothers of MRC may be less stressed financially than low social standard ones, however they found to be more concerned with the stigma associated with having such child.

Mothers are mainly concerned about the emotional strain of caring for their retarded child, about the readjustment of the family's daily routine and the additional time involved in caring for the child, regardless their social standard.

Regarding parenting stress in mothers according to child's sex, the result was insignificant ($P > 0.05$), along the three domains of the questionnaire, a result that came in accordance with that of Dyson (1993) and Brinker et al., (1994).

Although our result was found to be insignificant, yet the mothers of mental-

ly retarded females experienced higher level of stress than those of males along the three domains of the questionnaire. This could be explained by the fact that in our culture we are more protective towards females and more concerned about their future.

Insignificant result was found regarding the correlation between parental age and total stress score "table 8". A result that came in accordance with that of Flynt & Wood (1989) and Seltzer & Krauss (1989). This could be interpreted by the fact that more help is usually provided by other children who also grown older. Neighbours, relatives and friends know by time the child's problem and socially the burden is decreased.

Positive correlation between I.Q. and total stress score was evident "table 8". A result that came in accordance with that of Minnes (1988) and Donovan (1988). So, as level of I.Q. decreased children behavioral problems increase and communication skills decrease. Again, severely retarded are usually accompanied by other disabilities e.g. epilepsy. Also, chance to become educable or trainable mentally retarded decreases.

As regards correlation between child's age and total stress score "table 8", result proved to be statistically insignificant ($P > 0.05$). This result came in accordance with that of Flynt & Wood (1989), Beckman (1991) and Dyson (1993). We interpreted that by the fact that stress does not increase or decrease by child's age but by stressful events that differ from time to time e.g. time of initial diagnosis, onset of puberty. . . .

Psychiatric disturbances among parents were estimated by "Symptom Check List 90", (SCL, 90) and by clinical psychiatric interviewing "table 5". Depression was significantly prevailing among parents of MRC as well as par-

ents of PDC (X 19.293 and 19.488 respectively) compared to parents of NC (X13.500). Results that came in accordance with that of Friedrich & Friedrich (1981), Chetwynd (1985); Shapiro & Tittle (1986); Breslaw & Davis (1986); Stoneman & Crapps (1988); Beckman (1991) and Thompson et al (1992).

Additional and unusual caregiving demands associated with caring for a handicapped child are related to increased feeling of depression and decreased feelings of parenting competence which increase the feelings of depression.

The same result was found regarding anxiety score "table 5" which was found to be significantly prevailing among parents of MRC and PDC, and could also be interpreted by the same facts as in depression.

Hostility was found to be significantly lower among parents of MRC and PDC than those of NC "table 5". Although it was expected to have a high hostility scores among parents of MRC due to high level of stress, anxiety and depression they experience from their difficult situation, yet we found positive attitudes and even overprotection to be replacing hostility "table 7".

It seems that understanding the cultural impact could explain this result. The mentally retarded child is considered irresponsible for his or her acts and unable to understand. Religious beliefs and concepts in Egypt play an important role in increasing the parents' tolerability. El-Guindy et al (1994), found such positive attitudes among parents of MRC.

Although Psychoticism score was significantly higher ($p < 0.05$) among parents of MRC than NC, yet clinical assessment proved that only neurotic disorders were present. This could be

explained by the very high level of stress that the parents were exposed to, but it seems that a high level of tolerance to stress and psychic pain protect them from psychotic breakdown.

Physical examination revealed significant prevalence of affection of neurological system among parents of PDC e.g. cervical and lumbar spondylosis, which could be explained by the physical effort they do in carrying their children.

Many concerns were expressed by parents during interviews "table 9". Death fears was expressed by 87.7 % of parents of MRC. The main concern was about who would take care of their child after death. Fear of next pregnancy was expressed by 22%. Impact of MRC upon his or her siblings was expressed by 26.8%, the main concern was that could the MRC affect his siblings studying, self-esteem and even marriage. A variability of good community services and its improvement of MRC properties was expressed by 76.6% of parents of M.R.C.

Another concern was about the onset of puberty of MRC which was expressed by 31.7% of parents. Masturbation in public and sexual behaviors towards opposite sex and trying to teach the MRC to stop that was a difficult task.

Impact of other accompanying medical conditions was expressed by 26.8% of parents of MRC, as for example treatment required for a congenital heart diseases. Travelling abroad or to larger cities and its financial impact, seeking medical treatment was expressed by 34.2% of MRC. Many concerns that through light on the difficulties and the worries, the parents of MRC are facing and experiencing and which should be considered.

Recommendations

The results of our study through light on some important requirements that could be crystallized in the following recommendations:

1- Encouragement of premarital and marital counselling in our culture that emphasize the hazards of positive consanguinity which is prevailing in our Egyptian culture.

2- Improvement of prenatal, natal and postnatal care for prevention of mental retardation.

3- Further studies of fathers of mentally retarded child who were not presenting in this study.

4- Improvement of the quality of schools for mentally retarded children, to provide a better environment for them and to ensure more healthy and positive parental attitudes.

5- Special care for parents of mentally retarded child who were found to be suffering and exhausted, should be considered in the management of cases of mental retardation.

6- The role of psychiatrist should be emphasized in schools of mentally retarded children to provide support, help and guidance to parents of mentally retarded child.

7- Encouragement of the effort of social organizations (governmental and non governmental organizations (NGO's) in playing their effective roles in rehabilitation of mentally retarded and helping parents of mentally retarded child and supporting them.

8- Encouragement of parents of mentally retarded child whose situation is suitable to play an active role (formal and volunteerly) with their mentally retarded children in their rehabilitation schools, beside encouraging all parents to play their active role at home.

9- Encouragement of parents of mentally retarded children to organize a family association that can play a role in supporting the parents through this self help group of parents.

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L'impact des Oligoprénés Sur Leur Parents.

Dans cette étude, une enquête détaillée sur les parents d'oligoprénés, comparés aux parents d'enfants ayant un handicap physique et des parents d'enfants normaux a été faite, ayant pour but de mettre en évidence l'impact des oligoprénés sur leurs parents.

Chacun des trois groupes compatibles concernés fut divisé en deux sous - groupes (condition socio - économique , haute ou basse).

Les résultats furent discutés, les conclusions furent conclues .

أثر وجود طفل متخلف عقلياً على الوالدين

صممت هذه الدراسة للبحث في آباء وأمهات الأطفال المتخلفين عقلياً مقارنة بآباء وأمهات الأطفال ذوي الإعاقات البدنية (العضوية) وآباء وأمهات أطفال غير مصابين بهذه الإعاقات في محاولة لإلقاء الضوء على أثر وجود الطفل المتخلف عقلياً على والديه . وأعيد تقسيم الأسر في كل مجموعة حسب المستوى الإجتماعي وأستخدمت اختبارات نفسية متعددة إشتملت على جمع معلومات عن تاريخ الحالة للأطفال والفحص الطبي الشامل لهم وتطبيق مقياس وكسلر للذكاء، كذلك جمع بيانات خاصة بالوالدين وتطبيق مقياس الضغوط الوالدية وقائمة مراجعة الأعراض ومقياس الإتجاهات الوالدية نحو المعاقين وكذلك فحص نفسى وطبى شامل للوالدين في كل الحالات. وقد أظهرت النتائج ارتفاع نسب زواج الأقارب في والدى الطفل المعاق ذهنياً وتعرضهم لدرجة كبيرة من الضغط النفسى وكذلك لأعراض الاكتئاب والقلق المختلط واضطرابات الهلع ولقد وجد أن لوالدى الطفل المعاق ذهنياً إتجاهات إيجابية نحو المعاقين وكما كانت نسبة أعراض العداوة منخفضة فيهم . وقد أظهرت الدراسة أيضاً تزايد معدلات الضغط النفسى عند الوالدين مع إنخفاض ذكاء الطفل كما أدى وجود قرابة بين الوالدين لزيادة الإتجاهات السلبية نحو المعاقين. وقد عبر والدى الطفل المعاق ذهنياً عن زيادة الضغط النفسى لديهم في مواقف مختلفة مثل معرفتهم للتشخيص للمرة الأولى والخوف أثناء الحمل التالى، كما عبروا عن قلقهم من آثار وجود هذا الطفل المعاق ذهنياً على أخوته كذلك وصول الطفل المعاق إلى سن البلوغ والخوف عليه في حالة وفاة الوالدين . ولقد أوصت الدراسة بضرورة وجود برامج لزيادة الوعي عن مخاطر زواج الأقارب وضرورة تحسين الخدمات الطبية المقدمة للأم في فترة الحمل والولادة وضرورة رعاية أمهات الطفل المعاق ذهنياً وتحسين نوعية مدارس المعاقين ذهنياً ومشاركة الوالدين في نشاطات هذه المدارس . كما أكدت الدراسة على دور المؤسسات الإجتماعية الحكومية وغير الحكومية وضرورة مساندتها .