

Original article

Psychosocial impact on the Parents of mentally retarded children in Anand District

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Abstract

Background: The diagnosis of mental retardation in a child can trigger a range of emotional responses in parents & across family systems.

Objectives: The objective was to know the psychosocial impact on the parents having a child with mental retardation & its relationship with type of mental retardation.

Materials & Methods: A cross sectional study of 100 parents of mentally retarded children who were enrolled during 2006 at Mitra Rehabilitation School, a special school for mentally retarded children in Anand district, Gujarat. Study was done using NIMH DISABILITY IMPACT SCALE of National institute for the mentally handicapped, Secunderabad. Statistical Package for Social Sciences (SPSS) software was used to compute the χ^2 and ANOVA tests.

Results: There were 45% having mild, 46% with moderate and 9% with severe mental retardation, out of which 69% were male and 31% were female. There was no significant association found between specific thoughts of parents & type of mental retardation. There was no significant loss of support to parents from spouse, family, in laws, relatives, friends and neighborhood. Unemployed fathers had significantly (P value-0.04) more negatively affected relationship than the rest of the fathers. There was not significant association found between type of mental retardation and sibling effects.

Conclusion: Parents have enormous emotional problems and suffer from mental worries because of having a child with mental retardation. Family intervention programmes need to be focused on early building and strengthening the natural support systems for the parents.

Key words- Psychosocial impact, Family, Mental Retardation.

Introduction

Mental retardation(MR)is a condition of incomplete development of the mind, which is

especially characterized by impairment of skills, manifested during the development periods, which contribute to overall level of intelligence¹ The diagnosis of mental retardation in a child can trigger a range of emotional responses in parents & across family systems. For some, it will constitute a crisis that requires extraordinary psychological adjustment on a parent's part and contains elements of harm, loss and weakness. For others the birth of a disabled child will be viewed as an unfortunate event, yet one that has positive implications; it may provoke psychological growth in some family members. The initial parental response may be a form of emotional disintegration. This may evolve into a period of adjustment and later into reorganization of the family's daily life.² Mental deficiency and maladjustment has become an alarming universal problem in this existing society.

Objectives

The objective was to know the psychosocial impact on the parents having a child with mental retardation & its relationship with type of mental retardation.

Methods

Study design: A cross sectional study of psychosocial impact on the parents of mentally retarded children was conducted from August 2007 to August 2008. All children were fulfilling the International Classification of Diseases 10th Revision (ICD-10) criteria of mental retardation and diagnosed as mentally retarded child by psychiatric who regularly visit the school(once a week).¹

Sample size: Mitra Rehabilitation School of Anoopam Mission is the only one special school for mentally retarded children in Anand district. In our school based study, we had included 100 parents of all children with mental retardation who enrolled during 2006 at Mitra Rehabilitation School of Anoopam Mission.

With permission of school principal for the study, information regarding the purpose of the study, method of collecting information,

protection of confidentiality and total time required to collect information was conveyed to all the participants through parents meeting in school.

Method: Information was gathered about these children and their parents on specially designed semi-structure sociodemographic sheet. Study was done using NIMH DISABILITY IMPACT SCALE of National institute for the mentally handicapped, Secunderabad.³ All the interviews were conducted by main author in the homes of the participants with the language of their preference. The psychosocial areas of impact study included in this paper are family support, relationship, sibling effects, specific thoughts & positive impact. Parents were asked open ended questions to elicit information on the impact of having child with mental retardation. Each interview with parent lasted about 15-30 minutes depending upon how elaborate the respondent was.

Ethical issue: study was started after getting approval from Human Research Ethical Committee, Pramukhswami Medical College, Karamsad. The study involved the filling up of questionnaires, which would not cause any harm to the subjects. Purpose of survey was explained to the subjects. Informed consent was taken from the subject before inclusion in the study. They were free to discontinue interview at any stage. The information thus obtained was kept confidential.

Analysis: χ^2 (Chi-square) and ANOVA (Analysis of Variance ratio test) tests were used to find out association between different variables with the help of "Statistical Package for Social Sciences" (SPSS) software.

Results

There were 5% of the mentally retarded children in the age group of less than or equal to 5 years(≤ 5 years), 50% in 6-12 years,29% in 13-18 years and 16% in 19-28 years [Table 1]. Of the mentally retarded children, there were 69% male and 31% female.

| Age | Mental Retardation | | | Total |
|--------------|--------------------|-----------|----------|------------|
| | Mild | Moderate | Severe | |
| ≤ 5 | 2(4.4) | 3(6.5) | - | 5 |
| 6-12 | 27(60) | 20(43.5) | 3(33.3) | 50 |
| 13-18 | 10(22.2) | 14(30.4) | 5(55.6) | 29 |
| 19-28 | 6(13.3) | 9(19.6) | 1(11.1) | 16 |
| Total | 45 | 46 | 9 | 100 |

*Figures in Parenthesis indicate percentage, χ^2 value: 6.11, P value - 0.410.

There were 51% children belonged to nuclear family and 49% children belonged to joint family. There was no significant association (P value - 0.954) found between type of the family and type of mental retardation.

98% of the parents were getting support from spouse, relatives, friends and neighbourhood, only 2% had loss of support from them. There was not significant association (P value: 0.93) found between type of mental retardation and support from members.

There was no major impact found on relationship. There was not significant association (P value: 0.61) found between type of mental retardation and relationship. There was also not significant association of relationship with loss of support, sibling effects and specific thoughts. The parents who had more affected relationship also had more loss of support.

Regarding father's occupation, there were 45% of the father were doing service, 39% business, 8% labour,5% farmer, and 3% unemployed. Unemployed fathers had significantly more negatively affected relationship than the rest of the fathers [P value-0.04, Table 2].

| Father's occupation | Affected relationship (Mean difference between two groups) | Group | Group | P value |
|---------------------|--|-------|-------|---------|
| 1.Business | 0.61 | 1 | 5 | 0.005 |
| 2.Service | 0.24 | 2 | 5 | 0.002 |
| 3.Farmer | 0.60 | 3 | 5 | 0.009 |
| 4.Labour | 0.00 | 4 | 5 | 0.002 |
| 5.Unemployed | | | | |

ANOVA table, df-4, F value-2.20, P value - 0.04.

| Sibling effects | *Total (N=100) |
|-------------------------------------|----------------|
| Getting less time for you | 54 |
| Studies getting affected | 41 |
| Recreational need being compromised | 40 |
| Having added responsibilities | 35 |
| Feeling isolated | 22 |
| Teased by community | 19 |
| Worrying about future | 12 |
| Other effects | 1 |

*Total No. is 100, so numbers are equivalent to percentage

There were various sibling effects shared by parents of mentally retarded children [Table No.3]. There was not significant association (P value: 0.08) found between type of mental retardation and sibling effects [Table 4].

Table 4: No. of parents according to types of mental retardation with sibling effects

| Type of MR | Number | Mean | S.D | S.E |
|------------|--------|------|------|------|
| Mild | 45 | 4.02 | 3.74 | 0.55 |
| Moderate | 46 | 2.70 | 2.85 | 0.42 |
| Severe | 9 | 2.00 | 3.04 | 1.01 |
| Total | 100 | 3.23 | 3.35 | 0.33 |

ANOVA table, df-2(between groups) F value - 2.52, P value-0.08

There were various specific thoughts come to the mind of parents because of having a child with mental retardation. There was no significant association (P value-0.67) found between specific thoughts of parents of mentally retarded children & type of mental retardation.

There was not significant association (P value: 0.828) found between type of mental retardation and positive impact. In our study we found that more than 50% of the parents had positive impact in terms of patience, tolerance, empathy, sensitivity, support and relationship.

Discussion

A family who has a child with a mental retardation will experience many challenges such as “repeated physical and emotional crisis, interactive family issues, ruined schedules, and additional expenses, which can create financial burdens for a family”.⁴ It may be during these times of physical and emotional stress that parents will take out their frustrations on each other, the other children or even the child with the disability or illness.

Prevalence of mental retardation is 3% all over the world. However 75% of them fall into mild mental retardation category, while the rest 25% having IQ (Intelligence Quotient) of below 50 are classified as moderately, severely or profoundly retarded. Severe mental retardation is uncommon.^[1] There were 45% having mild mental retardation, 46% moderate retardation and 9% with severe mental retardation. In our study mild mental retardation is 45%, reason for this may be the diagnosis of mild type is usually late & difficult and it is school based prevalence. Generally mild type is diagnosed at later stage due to less awareness in community and when diagnosed it may be converted into moderate type that is easily recognized by

community people also. Another possibility that the parents may put their mentally retarded child to the school at later stage where mild would be converted in moderate type or more severe form. Mild mental retardation is usually difficult to diagnose especially during infancy.

Even people with mental retardation can give and receive affection like others. A happy family is one that recognizes this fact and takes pleasure in even their small achievements. In our study 51% children belong to nuclear family and 49% children belong to joint family. There was no significant association (P value - 0.954) found between type of mental retardation and type of the family. This may be due to our Indian cultural system and support from the family.

Family support is conceptualized from a social model of disability involving a consideration of the wider context in which families lives. Parents having mentally retarded children require mutual support from spouse, family and other members of society. The presence of behavioral problems in children is known to produce greater stress for parents. Managing such problems requires more effort and skill in handling them, and hence such support would be considered as important factor.

In our study there was no significant loss of support from spouse, family, in laws, relatives, friends and neighborhood. 98% of the parents were getting support from spouse, relatives, friends and neighborhood, only 2% had loss of support from them. When we see the family perspective, 87% had support from the family while 13% had no support from the family. 90% had support from in-laws while 10% had loss of support from in-laws.

Hodapp and Zigler opined that additional help need to be given to families with mentally retarded children to avoid making families with handicaps into “handicapped families”. It is true that when there is support, the stress experienced by parents is less. In the studies reviewed here, it is noticed that main support comes from the spouse.⁵

Moudgil, Kumar and Sharma noticed that those parents who get maximum social and emotional support from spouse and family members, parents, relatives and friends; experience less stress and problems.⁶

A study of facilitators and inhibitors that affect coping in parents of children with mental retardation by Reeta peshaweria, they found that mothers reported "Physical support - family" as a significantly greater facilitator in comparison

to fathers. Since mothers are more under pressure to balance child care needs and household chores, physical support from the family is reported as a relief.⁷

The impact of children with mental retardation on parents and other family members has long been of interest to professionals. Consequently understanding of relationships within the family has grown considerably over time. There was no major impact found on relationship. There were 5% of parents had somewhat affected relationship with spouse, 12% with family members, 12% with in-laws and only 2% with neighbors, friends and relatives. There was not significant association found between type of mental retardation and relationship.

The more dependent the child, the more adverse was his effect on his siblings. In other words, the more responsibility required by the normal siblings (particularly girls), the less likely the handicapped child would be welcomed into the family by his brothers and sisters.

The parents require devotion of more time to mentally retarded child than normal child and this might create bad impact on the siblings. 54% parents felt that they were giving less time to siblings. 41% parent felt that siblings study were got affected because of more attention to mentally retarded child. 35% parents felt that siblings had added responsibilities as they had to take care of mentally retarded child, more frequently seen in older female siblings. 40% sibling's recreational needs were also compromised as parents require more care & time for mentally retarded child. 19% of siblings were teased by community and 22% siblings who felt isolated because of mentally retarded sibling.

Many children can adapt themselves to the presence of a disabled sibling but that they tend to adopt the attitudes of their parents towards the family situation. Jealousy and resentment may also develop, if the handicapped child requires most of his parent's attention, leaving short tempers and impatience for the others. Since siblings may feel jealous, embarrassed and naturally left out due to the extent of attention given to the child with the disability or chronic illness. The parents require devotion of more time to mentally retarded child than normal child and this might create bad impact on the siblings.

Stress of mentally retarded child may give rise to various types of thoughts to the parents that may have negative and positive impact on them. 35% of the parents would never think for

another child as they felt that they were unable to take responsibilities of another child and they had already lots of struggle because of mentally retarded child. There were 33% of the parents who had sometimes thought of separating the child from the family so this child did not affect the rest of family members. Parents told that sometimes there might be problem in the family because of special attention, care and unsocial behaviour of the mentally retarded child. 26% of the parents had once also thought of suicide as they had the burden of a mentally retarded child with family responsibilities and many other factors related to these matters.

A study by Mohammadreza Bayat et al. found that the parents of mental retard children experience more psychological problems in aspects of aggression, depression, obsession, anxiety, physical complaint and psychosis than parents of normal children.⁸

Mita Majumdar et al found that the parents of mentally retarded children are more vulnerable to stress than parents of normal children. The high level of stress experienced by parents of mentally retarded children could be related to subjective factors such as a feeling of being restricted, social isolation and dissatisfaction, and might have paved the way for the manifestation of anxiety symptoms.⁹

Mentally retarded children have positive and negative impact on the family of mentally retarded children. In our study we found that more than 50% 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.

However, certain findings presented a reverse picture. Stainton & Besser reported that mothers of severely disadvantaged children have a positive impact of children with an intellectual disability on the family.¹⁰

Conclusion

Parents have enormous emotional problems and suffer from mental worries because of having a child with mental retardation. Family focused early intervention programmes need to be focused on early building and strengthening the natural support systems for the parents.

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