



Impact of Disability and Coping Strategies Among The Parents of Children With Intellectual Disabilities

KEYWORDS

Intellectual disability, Stress, Coping strategies, Intervention programmes.

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ABSTRACT

Intellectual disability originates during the developmental period and results in significantly sub average general intellectual function with concurrent deficits in functional life skills. The nature and degree of positive and negative impact of intellectual disability on parents and their coping strategies were studied. Thirty intellectually disabled children fulfilling the ICD-10 criteria of intellectual disability were selected from special schools in Jammu district of J & K state. Seguin form a board intelligence test, National Institute for the Mentally Handicapped Disability Impact Scale, Family Interview for Stress and Coping in Mental Retardation, (FISC-MR), Section 2 were the tools administered on the parents. The result shows that parents have more positive impact (52.77%) than the negative impact which is 31.47%. And most of the parents were having better coping strategies as measured on Likert scale.

Intellectual disability originates during the developmental period and results in significantly sub average general intellectual function with concurrent deficits in functional life skills. According to the latest edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*, three criteria must be met for a diagnosis of mental retardation: an IQ below 70, significant limitations in two or more areas of adaptive behavior (as measured by an adaptive behavior rating scale, i.e. communication, self-help skills, interpersonal skills, and more), and evidence that the limitations became apparent before the age of 18. The parents are usually adamant to accept the fact of diagnosis of intellectual disability in their child which triggers a range of emotional responses. The objective of the present research is to study both the positive and negative impact of disability on the parents of intellectually disabled children and their coping strategies. Depending upon severity of intellectual disability, these children are more and more dependent on their parents or caretakers. Having an infant with a serious health condition or health risk increases the likelihood that parents divorce or live apart. It also leads to a reduction in the father's or mother's working hours. Parents with disabled child have lower rates of social participation than parents without a disabled child and they are less likely to have large families.

Need of the study

There is immense need to study the nature and degree of positive and negative impact of intellectual disability on parents and their coping strategies so as to objectively design and evaluate family intervention programmes.

Objectives of the study

1. To study the positive and negative impact of intellectual disability on parents.
2. To assess the coping strategies among the parents of children with intellectual disabilities.

Sample

The sample comprises of parents of the children selected from special schools in Jammu district of J & K state. Thirty intellectually disabled children fulfilling the International Classification of Diseases-10 criteria of intellectual disability and diagnosed as intellectually disabled children by psychiatric visiting these special schools were selected. Both mothers and fathers were interviewed. Purposive sampling technique was used to select the sample.

Tools used

All the intellectually disabled children were diagnosed by a

consultant psychiatrist using the ICD-10 criteria. The Intelligence Quotient of the children with intellectual disability was assessed by using Seguin form a board intelligence test.

A semi structured socio demographic sheet was prepared to elicit information about the parents which included (i) specific variables of the child such as age, sex and severity of intellectual disability. (ii) Socio demographic variables such as parental age, education, occupation, family income and type of family.

National Institute for the Mentally Handicapped disability Impact Scale was used to assess the impact of disability on caregivers of the children with intellectual disabilities. This is a culture specific tool which could be used to identify and assess the following:

1. The nature and degree of impact on the parents (both positive and negative) because of having a child with mental retardation.
2. The nature and degree of impact on the family members and the relationship within the family.
3. The nature and degree of impact with regard to relationships outside the family.
4. To identify trust area for family intervention programmes.
5. To objectively evaluate family intervention programmes.

The 11 areas of impact included in the scale are physical care, health, career, support, financial, social, embarrassment/ridicule, relationships, sibling effects, specific thoughts and positive effects. Scale is used for mother and father at the same session and rating was done immediately after all questions asked from the parents.

Parents were administered the Family Interview for Stress and Coping in Mental Retardation, (FISC-MR) Section 2, a semi structured interview, developed by Dr. Girimaji at NIMHANS Bangalore. The tool consists of 2 sections:

1. Measuring Stress (Daily care, emotional stress, social stress and financial stress) and
2. Measuring mediators of stress or coping strategies (awareness, attitudes & expectations, child rearing practices, social support and global adaptation).

Section two has 5 areas and 9 subscales and Coping scores were measured on Likert scale. Percentage of families on various score grades was calculated.

Procedure

Thirty intellectually disabled children fulfilling the International Classification of Diseases 10th Revision (ICD-10) criteria of intellectual disability were selected from special schools in Jammu district of J&K state. The parents of the children with age group 5 to 18 years were selected as sample. The children having both the parents were selected. Purposive sampling technique was used to select the sample. Consent from the parents was taken to conduct research. Information was gathered about these children and their parents on specially designed semi structured socio- demographic sheet which included (i) specific variables of the child (ii) Socio- demographic variables of parents. Seguin form a board intelligence test was administered to assess their intelligence. Disability Impact Scale was administered to study the positive and negative impact of intellectual disability on the parents. Parents were then administered with Family Interview for Stress and Coping in Mental Retardation, Section 2 to assess their coping strategies.

Results

Table – I Socio-demographic details of parents of intellectually disabled children

Variable	N	Range	Mean	SD
Age	60	23-53	40.8	7.12
Variables	n	Percentages		
Sex				
male	30		50	
female	30		50	
Education				
up to primary	07		11.67	
up to hr. secondary	21		35	
up to graduation	26		43.33	
Illiterate	06		10	
Occupation				
unskilled worker or farmer	12		20	
business	10		16.67	
service	18		30	
housewife	20		33.33	
Domicile				
urban	18		30	
rural	42		70	
Income (INR)				
1000-10000	08		13.33	
10001-25000	30		50	
above 25000	22		36.67	
Type of family				
Nuclear	36		40	
Joint	24		60	

Table I shows that the total of 60 parents were interviewed, their age range was 23-53 years with a mean 40.8 and standard deviation 7.12. 50% of the parents were males and 50% were females. Most of the parents (43.33%) were educated up to graduation, 35% of the parents were educated up to higher secondary level, 11.33% of the parents were educated up to primary level and about 10% of the parents were illiterate. In occupation, most of the mothers were housewives (33.33%), 30% of the parents were employed in service, 20% of them were unskilled workers. Most of the parents belonged to rural areas that are 60% while 40% of the parents belonged to rural areas. Income wise, majority of the parents (50%) earning ranges from INR 10,001 to 25,000, 36.67% of the parents earnings were above INR 25,000 and 13.33% of the parent's earnings ranges from INR 1,000 to 10,000. Most of the families were living in nuclear family setting (60%) while 40% of the families were living in joint family setting.

Table -II Impact of intellectual disability on the parents

Areas	Maximum score	Scores obtained	Percentage
Physical care	960	356	37.08
Health	600	180	30
Career	480	90	18.75
Support	720	224	31.11
Financial	600	195	32.25
Social	360	120	33.33
Embarrassment/ridicule	480	154	32.08
Relationships	720	250	34.72
Siblings affect	840	320	38.09
Specific thoughts	480	75	15.62
Total negative impact	6240	1964	31.47
Positive impact	720	380	52.77

Table II shows the percentage of both negative and positive impact on the parents of intellectually disabled children. The maximum negative impact on the parents was on sibling effect (38.09%) and physical care (37.08%), the minimum negative impact on the parents was on career (18.75%) and specific thoughts (15.62%). The percentage of negative effect on health, support, financial, social, embarrassment/ridicule, relationships was 30%, 31.11%, 32.25%, 33.33%, 32.08%, 34.72%. The results of the present study shows that parents have more positive impact (52.77%) than the negative impact which is 31.47%.

Table III Coping strategies among parents of children with intellectual disabilities.

S.No	Area	Sub area	Likert grade 1	Likert grade 2	Likert grade 3	Likert grade 4	Total
1	Awareness about the child's problem	General awareness	Largely adequate	Adequate	Slightly inadequate	Highly inadequate	100
			38	44	14	4	
		Misconceptions	No misconceptions	Misconceptions almost absent	Misconceptions present	Misconceptions present to a large extent	
			43	44	10	3	100
2	Attitude towards the mentally retarded child and expectations from her/him	Expectations from child	Largely appropriate	Mildly appropriate	Moderately inappropriate	Highly inappropriate	100
			40	24	30	6	

		Attitude towards the child as a person and family member	Most favourable	Favourable	Unfavourable	Most unfavourable	
			35	43	17	5	100
		Attitude towards child management	Most favourable	Favourable	Unfavourable	Most unfavourable	
			40	42	14	4	100
3	Child rearing practices	General rearing practices	Most favourable	Somewhat favourable	Somewhat unfavourable	Most unfavourable	
			42	42	12	4	100
		Rearing practices specific to training	Most favourable	Somewhat favourable	Somewhat unfavourable	Most unfavourable	
			33	37	18	12	100
4	Social support	Social support	Best social support	Adequate	Somewhat inadequate	No or very little	
			34	45	13	8	100
5	Global adaption	Global adaption	Extremely best	Adequate	Inadequate	Very poor	
			28	56	18	8	100

Table -III indicates that about 38% of the parents were highly knowledgeable about the cause, prognosis and treatment of their child's condition while 4% of the parents showed very poor knowledge in all the areas. 43% of the parents had no misconception while 3% had wide misconception regarding investigations and treatment of their child's condition. 40% of the parents had appropriate expectations from their child while 6% had highly inappropriate expectations. 35% of the parents had most favourable attitude towards the child as a person and a family member, whereas 5% of the parents had most unfavourable attitude. About 40% of the parents had most favourable attitude and 4% of the parents had most unfavourable attitude towards child management. Results indicates that 42% of the parents showed most favourable attitude in their general rearing practices adopted for the children with intellectual disabilities whereas 4% parents showed highly unfavourable attitude in general rearing practices. 33% of the parents show most favourable attitude to rearing practices specific to training while as high as 12% parents had most unfavourable attitude. 34% of the parents reported best social support available which they utilized maximally while 8% of the parents alleged having very little or no social support. The Global Adaptation score suggested that 28% families were extremely well adapted while 56% of the parents were adequately adapted to the presence of an intellectually disabled child. Of the remaining 44% families, 8% showed very poor coping, that is poor adaptation.

Discussion

A parent experiences multiple problems parenting with a disabled child and faces variety of emotions at every stage of their lives. They experiences more of positive impact than negative impact which may be due to changes in life style, standard of living, social changes and means of recreation and leisure activities and perception of the family members towards disabled child. Stainton and Besser (1992) found the positive impact of mentally retarded children in the family. They identified nine core themes in them viz, (1) source of joy and happiness, (2) increased sense of purpose and, (3) expanded social and personal networks, (4) community involvement, (5) increased spirituality, (6) source of family unity and closeness, (7) increased tolerance and understanding, (8) personal growth and strength, (9) positive impact on others/community. Blacher and Baker (2007) examined parents' perceived positive impact of a child with severe mental retardation or developmental delays. Positive impact was inversely related to behavior problems. Latina mothers reported higher positive impact than Anglo mothers did when the child had MR/DD. The percentage of positive impact of having a mentally retarded child outnumbered the level of negative impact of it. (Positive impact=55.38% vs. Negative impact = 26.26%) (Singh et al. 2008). Present research also indicates more of positive impact (52.77%) than negative impact (31.47%). The parents feel that they have developed more patience, more

tolerance, more empathy, more sensitivity, more support and better relationships among couples over the period of bringing up their child that may be due to better coping strategies being adopted by the parents.

The parents had both positive and negative emotions towards their children, such as sorrow and joy, pessimism and optimism. Their daily activities evolved around positive impact to negative impact. These may be due to the fact that parents tend to develop a sense of resilience to meet up the daunting task that is, fulfilling the needs of retarded children (Kearney and Griffin 2001). Mothers spent more time providing care, offered more types of support and perceived more care giving burden, in comparison with fathers of intellectually disabled children. The behavior and health of the children had a greater impact on mothers than on fathers (Heller et al.1997). The disabled child can have an integrative effect by focusing the family's energy in a concerned, loving manner, thereby minimizing some of the other day to day problems. Some parents expressed a new appreciation for life and ordinary things they used to take for granted (Mahoney 1953).

Research in India has indicated that receiving maximum social-emotional support from the spouse, family members, relatives, and friends are facilitators for effective coping. The physical support from within and outside the family is one of the greatest facilitators in coping (Peshwaria et al. 1995). Present research which indicates better coping strategies also indicates that 34% families reported best social support available which they utilized maximally and only 8% of the parents alleged that very little or no social support was available. Social support may enable people to gain access to perceptions that reduce feelings of threat or stress associated with an event; for example, comparisons with others may lead a person to perceive his or her problem as less difficult than those faced by others. The informal and professional supports available for families of children with mental retardation in Korea and USA showed that American mothers received more informal and professional support while Korean mothers experienced more stress. A good support system is required to operationalise support and training for families in our part of the world also (Jin and Shin 2001). The family support and cohesiveness were the positive elements to overcome the stress (Beavers et al.1986).

The results of the examination of psychosocial well-being of parents of autism affected children shows that parents who had better social support had lesser level of emotional symptoms like depression, anxiety, anger and parents of older autistic children had lower level of depression, anxiety, anger may be because of passing of time they learn to live with the problem (Gray and Holden1992). Some studies have noted increased stress among these families, other studies have indicated that families have tremendous resiliency and can

mobilize resources to cope with their particular challenges (Abbott & Meredith 1986; Bebko, Konstantareas & Springer 1987). The higher levels of stress are found in the families with handicapped children and that despite the presence of high levels of stress, the families were found to have successful coping strategies (Kazak and Marvin 1985).

A study designed to understand the differences in perceived disability impact and related coping in mothers having children with intellectual disabilities alone compared to those having children with intellectual disabilities and additional disabilities. Group differences for disability impact were present in specific domains but not overall. Both positive and negative coping strategies were observed in both groups. (Kishore 2011). Family coping using a pretested self-administered questionnaire was measured. 74% families were seen to have adequately adapted to having a mentally retarded child in their family, as measured on the global adaptation scale. The remaining 26% families had inadequately adapted, of which 7% showed poor coping (Farheen et al. 2008). Present research indicates 28% of the parents are extremely well adapted, while 8% of the parents show very poor coping or adaptation on global adaptation scale. The social support or self-help groups have become increasingly popular forms of family support among families who have children with disabilities (Pearson et al. 1986).

Suggestions

Parental training by government, non-government organizations, educational or research services and better parents caregivers relationship are essential in bringing about a positive change in the condition of children with intellectual disabilities and their families. Intervention programmes should be developed for the parents to enhance coping strategies. Support groups developed may also enhance coping strategies. Behavior modification training and counseling programmes should be designed to teach problem solving and communication which improves feeling of competence among parents and understanding child behavior in a better way. Associations among the family members having children with intellectual disabilities enhance coping strategies which may be supported and organized by professionals in related fields. Parents should meet others in similar situations and share positive experiences as it improves self esteem. The group leaders encourage the parents to share their own effective coping strategies with one another.

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