Original Article

Extent of Disability and Behavioral Disturbances of the Children with Intellectual Disability and the Coping Mechanisms of their Parents : An Observational Study from a Tertiary Care Hospital of Eastern India

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Background : Parents experience great challenge in bringing up their children with Intellectual Disability (ID). The present study was undertaken to examine the level of disability, magnitude and pattern of Behavioral Disturbances of the children with ID and the coping mechanism of their parents to combat against this great challenge.

Materials and Methods : The current observational study was conducted on consecutive 92 children (≤18 years) with mental retardation [Intellectual Disability (ID)] as per International Classification of Mental and Behavioral Disorders, Tenth Edition, Diagnostic Criteria for Research version (ICD-10, DCR) and their parents (<65 years) who was living with their children with ID. Socio-demographic data of both children and parents, Intellectual Quotient (IQ), level of disability of the children were assessed. Behavioral Disturbance of the children was assessed by Behavioral Assessment Scale for Indian Children with Mental Retardation (BASIC-MR) and coping mechanism of the parents was assessed by Brief Cope Questionnaire (BCQ).

Results : Majority of the children were male with mean age of the sample was 11.34 (SD 5.07) years with mean IQ was 79.87 (SD 11.28). Majority of the children (53%) had severe disability (≥ 90%). Children had high level of behavioral problems having higher scores in domain 1, 2 and 3 of BASIC-MR with mean scores were 105.79, 113.13 and 118.48 respectively. Majority of the parents were above 40 Years. A large portion of families came from upper middle class followed by lower middle-class background. Among the domains of BCQ, both parents had applied 'acceptance' (mean score of fathers 6.89, mothers 7.00), 'positive refraining' (mean score of fathers 5.93, mothers 6.00) and 'active coping' (mean score of fathers 6.13, mothers 6.00) mostly.

Conclusion : Parents, both the fathers and the mothers were using their coping strategies well to combat against their stress, on account of care-giving their disabled children.

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Key words **: Intellectual Disability (ID), Disability, Behavioral Disturbances, Coping Mechanisms, Parents.**

According to World Health Organization, Mental Retardation (MR) or Intellectual Disability (ID) is a condition of arrested or incomplete development of the mind, characterized by impairment of skills and overall intelligence in areas such as cognition, language and motor and social abilities (WHO, 1993)[1]. In developing country like India families especially parents have to take the prime role to raise their children with disabilities at home and in the society. Greater financial stress, frequent disruption in family functioning, reduced social interaction outside the family etc. are the basic issues that the parents have to deal with. It often becomes very challenging for parents to provide long term care to the child, can become a strain and may result into impacts on psychological and physical health and overall Quality of Life of the parents[2-8].

Parents of children with developmental disabilities experience higher level of stress to upbring their children in comparison to the parents with normally developed children[9-12]. Parents can experience stress in several spheres of their life facing the challenges of caregiving of their children, regarding relational

Editor's Comment :

- Children with intellectual disability attending Tertiary Care Hospital were at a significant level of disability and behavioral disturbances.
- The therapists should educate the parents as primary caregivers to enhance on several components of coping skills such as humor, planning, venting, self distraction etc to continue their battle of upbringing of their children as well as improve their own quality of life.

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problem[13], with financial constraints[14], feeling of decreased parenting efficacy[15] etc. The severity of stress perceived by the parents depends on the severity of the adversities in various sub-domains of their lives and their cognitive appraisal about the issues. Chronic unresolved stress can often compromise their psychological health[16]. By natural effort parents always try to cope with their stress by their own way actively or passively, that often depends on their psychological, social and cultural background and availability of resources. The term 'coping' refers to the behavioral strategies that an individual applies to reduce the effect(s) and or demand(s) of stress[17]. Folkman and Lazarus narrated coping efforts as the interaction of two separate cascades, ie, management of the person-environment relationship and regulation of associated stressful emotions. Lazarus (1980) defined coping as "the cognitive and behavioral efforts made to master, tolerate, or reduce external and internal demands appraised as taxing or exceeding the resources of the individual". These coping styles or mechanisms were described in the literature in different categories, subcategories and items[18]. In comparison to using maladaptive pattern of coping strategies such as negative emotion focused coping, using of healthy coping strategies such as problem focused coping, persons may manage their stress relatively in rational way and protect their psychological health better. There are studies available in the literature on the coping mechanism of parents with developmental disabilities but Indian studies are very scant[19-24]. The pattern of using coping of Indian parents might be different from the western counterpart as there is significant difference in their socio-cultural-economic milieu. Even fathers and mothers may have contrast in pattern of using coping strategies as per their social role in that specific family and in that society or community at large.

This present study was undertaken in a Tertiary Care Hospital of Eastern India, to understand magnitude and pattern of behavioral disturbances and the extent of disability in the children with ID and the pattern of coping behaviors of their parents, observed differentially for fathers and mothers.

Materials and Methods

In the current observational cross-sectional study, which was conducted at Psychiatry OPD of a tertiary care teaching hospital in Kolkata, West Bengal and consecutive 92 children (≤18 years) with ID as per ICD-10, DCR version[1] and their parents (<65 years, having children living with them) were included. Parents with chronic medical illness or ID were excluded from the study. Research protocol was approved from the Institutional Ethics Committee. Intelligence Quotient (IQ) was tested using standard scales [eg, Vineland Social Maturity Scale (VSMS)[25], The Denver Developmental Screening Test (DST)[26], Seguin Form Board (SFB)[27] or Binet Kamat Test (BKT) for Intelligence[28] as applicable by an authorized clinical psychologist. Level of disability of the children was measured in percentage as per Gazette of India notification[29]. Behavioral assessment of their child was done using Behavioral Assessment Scale for Indian Children with MR (BASIC-MR)[30]. Coping mechanisms of the parents were assessed using Brief Cope Questionnaire (BCQ)[31]. BASIC-MR is a scale to assess the current behavior of the children with Intellectual Disability (ID). As Brief Cope Questionnaire (BCQ) is a self-rater's scale, the scale was validated in Bengali and used in the current study by following a standard procedure of validation. Assessment will be done by an expert such special educator, psychiatrist. Standard Package of Statistical Software Version 20 was used for statistical analysis of the collected data.

Results

The study comprised of 92 children with ID and their parents (both father and mother).

(1) Description of Children :

The median age of children was 9.00 years, mean 11.34 years and Standard Deviation 5.07. Among the whole population 62% (n=57) of children were male and 38% (n=35) were female. Median, Mean, Standard Deviation of IQ and disability percentage of the children were 80.00, 79.87, 11.28 and 50, 38.83, 11.39 respectively. Among all children, 8 (8.7%) children had 50% or minor disability, 35 (38.04%) children had 75% or moderate disability and 49 (53.06%) children had 90% or severe disability (Table 1).

(2) Behavioral Disturbances of the Children :

Behavioral problem of the children in the current study were assessed by BASIC MR Part A and Part B. The distribution of scores across seven sub domains of BASIC MR Part A and Part B is described in Table 2.

Table 1 — *Distribution of Age, IQ and Disability percentage of the Children (N=92)*

Variables	Median	Mean	Standard Deviation (SD)
Age (in years)	9.00	11.34	5.07
IQ	80.00	79.87	11.28
Disability	50	38.83	11.39

Table 2 — *Distribution of the Scores of BASIC-MR of the Children (n=92)*

	Part A (domain wise scores)							Part B (composite score)
	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	
Mean	105.79	113.13	118.48	58.69	50.15	58.05	41.99	14.60
Median	108.00	110.50	113.50	52.50	53.00	48.00	29.00	10.00
SD	46.02	51.09	95.87	40.41	32.48	42.15	42.13	12.14

(3) Description of Parents and their Families :

The median age of the fathers who participated in the study was 50.00 years, mean 51.00 years, Standard Deviation 8.85. The median age of mothers was 45.00 years, Mean 44.32 years, Standard Deviation 8.65. Among the families 71.7% (n=66) were nuclear and 28.3% (n=26) joint. Regarding socio-economic status, 46.7% (n=43) belonged to upper middle class, followed by lower middle (n=35, 38%), upper lower (n=10, 10.9%) and upper (n=4, 4.3%) according to Modified Kuppuswamy's classification.

(4) Coping Mechanism among Parents :

The Brief Cope Scale doesn't yield any summary score. But for convenience of applying statistical tests the scores of 2 specific questions (which denote a specific type of coping mechanism, as per the scales) were added to calculate a score for each coping mechanism. Tables 3 show the distribution of these scores in 12 different areas of coping for both fathers and mothers.

Discussion

A cross-sectional observational study was done in a Tertiary Care Medical College in Kolkata to know the extent of disability and behavioral disturbances of the children with ID and coping mechanism of their parents.

With ID, the children have deficit in several domains in adaptive functions and different types of behavioral disturbances in the form of stereotypes, aggression, and violence that might lead to injury to self, to others, or destruction of property etc[31,32]. These behaviors are detrimental not only to the person himself who exhibits such behavior but pose a challenge to their teachers and caregivers. A behavior becomes challenging when it is of such intensity, frequency or duration that it threatens the safety of self or others. It is likely to lead to restrictive or aversive responses and exclude social participation. Earlier studies from the west have found that ~10% of persons with ID manifest severe challenging behavior ranging from self-injury, destructiveness, aggression, and disruptive behavior[33]. When milder forms of behavioral problems such as verbal aggression and temper tantrums are included, the prevalence goes up to 22.5 to 55%[34]. A study from India reported that violent and destructive temper tantrums and self-injurious behavior among persons with ID vary according to its severity[35].

In the current study, BASIC MR scores was used to assess the level of behavioral problem in these children. Part-A deals with skills behavior and higher score indicates higher skills behavior. It has 7 domains with 40 items each. The scoring is done from 0 to 5 so a maximum score that can be obtained by a child is 1400. The average BASIC MR-A score of the sample of current study was 569 with maximum score of 1281 and minimum score of 46. So, it can be understood that most of the children had average skill set but definite conclusion cannot be reached as it was a heterogenous group. The BASIC MR, Part-B score is the indicator of behavioral issues or undesirable behavior. Total 75 tests are done and scored from 0 to 2. So, the maximum score that a child scored is 150. In the current study sample the average score was around 15 with maximum score was 50 and minimum score was 0. Which indicates a low level of behavioral problem in this particular group with a wide variation that's not always corroborated with IQ level. But this study still shows that a significant number of behavioral problems is found in children with MR.

In the current study most of the parents had applied positive modes of coping such

Tables 3 — *Distribution of scores of Brief Cope Scale of the parents (N=92)*

Items of Brief Cope Scale	Fathers			Mothers		
	Mean	Median	SD	Mean	Median	SD
Self blame	3.14	2.00	1.43	3.11	3.00	1.48
Religion	3.97	4.00	1.72	3.62	3.00	1.65
Acceptance	6.89	7.00	1.57	6.43	7.00	1.78
Humor	2.23	2.00	0.79	2.13	2.00	0.54
Planning	5.82	6.00	1.65	5.57	6.00	1.83
Positive reframing	5.93	6.00	1.59	5.79	6.00	1.74
Venting	2.97	2.00	1.29	2.97	2.00	1.36
Instrumental support	4.87	5.00	1.85	4.68	5.00	1.88
Emotional support	4.63	4.00	1.72	4.27	4.00	1.76
Substance use	2.04	2.00	0.29	2.09	2.00	0.45
Behavioral disengagement	2.85	2.00	1.38	2.89	2.00	1.29
Active coping	6.13	6.00	1.77	6.04	6.00	1.93
Denial	2.92	2.00	1.82	2.80	2.00	1.64
Self distraction	4.03	4.00	1.76	3.82	4.00	1.56

as acceptance, positive refraining and active coping to combat against their stress out of caring their disabled children. Education level of both fathers and mothers of the current sample were reasonably high and most of them belonged higher socio-economic classes in reference to national average level. Similar observation was reported from other Indian study[22] where the association between higher education and use of healthy pattern of using coping strategies by the parents was also noted. Few other Indian research tried to study the gender difference among the parents in terms of perceived stress on account of the caregiving of children with developmental disabilities. In general, it was reported in the literature that the Indian fathers would perceive and cope to their stress more positive way than the mothers[17]. The difference in social role among the fathers and mothers in Indian society can explain this differential observation. However, in the current study no significant difference was observed among the parents in this regard. Current social reforms in the Bengali community and at large in the Indian society might be the possible explanation.

Conclusion

Parents with children with ID having significant disability and behavioral disturbances were using their coping strategies well to combat against their stress, out of caregiving their disabled children, being comparable for both fathers and mothers in Indian community.

Limitations :

It was a hospital-based study done in a metropolitan city on a relatively small study population. The current research was planned as a descriptive study. So, inferential statistics was not attempted which would have greater significance and larger clinical implications. Multicentric study with a large and variable sample is needed in future to explore the issue further.

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