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Research Paper

Mental Health Issues among Parents of Children with and without Intellectual Disability

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ABSTRACT

The term Intellectual disability is a diagnostic term denoting the group of disconnected categories of mental functioning such as idiot, imbecile, and moron derived from early IQ tests, which acquired pejorative connotations in popular discourse. In the definition released by AAMR (Luckasson et al., 2002), mental retardation was described as a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social and practical adaptive skills. The present study assessed the mental health issues among parents of children with and without intellectual disability. Parental Stress Index (PSI) (Abidin, 1995), was used to identify sources of stress in parent child sub systems. The Norbeck Social Support Questionnaire (NSSQ; Norbeck et al, 1995), was used to assess rates of the extent of perceived emotional support. Family Support Scale (Dunst et al, 1984) was used to assess the sources of family support available. Centre for Epidemiological Studies Depression Scale (CED-D; Radloff, 1977) was used to assess the current levels of depressive symptoms and mood. All these were administered on 120 mothers of Intellectual disabiled (ID) children aged 10 to 20 years and 120 mothers of healthy children with average intelligence (AI) as controls. The results revealed that, overall mothers of children with ID reported higher level of stress and are more depressed than mothers of children without ID. On the other hand, in terms of social and family support, mothers of ID children had significantly higher emotional support than mothers of children without ID. This may also be a reflection of the fact that even though in India the structure of the family has become nuclear; functionally families still operate within an extended social network.

Keywords: *Intellectual Disability, Care-givers, and Mental Health Issues*

The term Intellectual disability is a diagnostic term denoting the group of disconnected categories of mental functioning such as idiot, imbecile, and moron derived from early IQ tests, which acquired pejorative connotations in popular discourse. The term intellectual disability acquired pejorative and shameful connotations over the last few decades due to the use of the words retarded and retard as insults. There are many definitions of mental retardation, most comprehensive among them is the one given by the American Association of Mental Retardation (AAMR).

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In the definition released by AAMR in 2002 (Luckasson et al., 2002), mental retardation was described as a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social and practical adaptive skills. This disability originates before age 18. Typically, an intellectual level that is considered to be within the range of intellectual disability, as measured on an IQ test, is two or more standard deviations (SDs) below the mean, resulting in a level of 70 IQ points or lower when using an IQ test with a mean of 100 and a SD of 15.

All of us have many dreams and whenever a person loses his/her dreams, it brings major changes in his/her personality and in his environment. Parents have many dreams about their children and when a disabled child is born, parents go through dramatic changes, a state of grieving that effect on parent's health, attitude, personality, priority, values & beliefs, along with it changes their routine activities. It is commonly observed that if one child is disabled in family, parents usually suffer with different emotional and psychological problems. The reasons of parental depression, anxiety and stress were explained by Sousa & Singhvi (2011) i.e., "society considers parenting is a positive thing, but it views the birth of a disabled child negatively. This attitude by society produces stress among family members. The marital relationship may suffer excessively due to the stresses of guilt, shame, blame and anxiety.

Objective

- The main objective of the study was to compare stress, copying and depression among parents of children with and without intellectual disability.

METHODOLOGY

Sample

The sample consisted of 120 mothers of Intellectual disability (ID) children aged 10 to 20 years and 120 mothers of healthy children with average intelligence (AI) as controls. Criteria for inclusion in the intellectually disabled children were, children with less than IQ of, (below 70, and no other physical disabilities). Parents of children who screened positive for intellectual disability (meeting DSM-V- criteria for intellectual disability, assessed and diagnosed by Clinical Psychologist, were enrolled in this study. Parents were included in this study if they were 1) aged 25 years and above; 2) were the main careers for an intellectually disabled child; 3) their child had a diagnosis of intellectually disability according to DSM V criteria and as diagnosed by clinical psychologist and 4) gave consent to participate in the study.

Mothers in the ID group were identified in the special schools in New Delhi and who had children diagnosed with Intellectual Disability. Parents of healthy children were recruited from the localities adjoining the special schools in New Delhi. Mothers in the two groups were matched on age, education, family income and age of the child. The mother's mean age was 27.28 years (SD=4.07). Majority (80%) had up to 12 years of formal education, were from urban (83%), nuclear families (74%) and had an average monthly income of Rs 7000.

Tools Used

The following tools were used for the present study:

Socio-demographic Performa: A special Performa designed for this study was used to gather socio-demographic details about the parents.

Measures

Parents were assessed on following measures:

- **Parental Stress Index (PSI) (Abidin, 1995)**: The Parental Stress Index is a 120-item clinical and research questionnaire designed to identify sources of stress in parent child sub systems. The PSI yield's stress score in three domains, child domain, parent domain, and life stress. In the child domain, subscales measured are child related stressors such as child's adaptability, acceptability of child to the mother (acceptability), demanding nature, moodiness, and distractibility (demanding nature, child mood and distractibility-hyperactivity) and degree to which the mother found the child reinforcing (reinforces parent). In the parent characteristic domain, sub scales measures are parent attachment to the child (attachment), restrictions imposed by the parental role (restriction of role), depression, social isolation, relationship with spouse/ parenting partner, parental health and evaluation of their competence (sense of competence). Finally, the life stress scale assessed the occurrence of 19 stressful life events over the previous 12 months, weighted for their potential impact. Eleven of the 19 life events can be considered negative (e.g death of the family members). The PSI has acceptable internal consistency, with alpha values ranging from .60 to .95, and adequate test-retest reliability ranging from .70 to .90 for a 3-4 week interval.
- **The Norbeck Social Support Questionnaire (NSSQ; Norbeck et al, 1995):** The NSSQ is a self-administered measure that rates the extent of perceived emotional support (e.g., affect, affirmation), aid (tangible support) and network structure (i.e., size and frequency of contact). In an interview format, the respondent is asked to generate a list of significant others in his or her life (network size) and then to answer a series of structured questionnaire that allow for measurement of parent's satisfaction with each person nominated. The NSSQ may be scored to obtain information on the sources of support and the relative contribution of friends, family members, and healthcare professionals to perceptions of support. Internal consistency estimates range from .69 to .98 and test-retest reliabilities of .85 to .92 have been reported.
- **Family Support Scale (Dunst et al, 1984):** This scale consists of 18 sources of family support, including parents, friends, spouse, coworkers, church/temple, and professional agencies and so on. Parents are also invited to rate others if source of support is not included in this questionnaire. Parents rated whether each source of support was available and if available, whether the source was not at all helpful to extremely helpful on a scale of 0 to 4. The final score was obtained by adding together the ratings on each of the items.

- **Centre for Epidemiological Studies Depression Scale (CED-D; Radloff, 1977):** The CES-D is a 20 item scale designed to measure current levels of depressive symptoms and mood in the general population. Several fields studies have reported internal consistency coefficients of .84 to .90 and there is evidence that CES-D converges with other measures of depression.

Procedure

Following an initial screening, prospective subjects were contacted through special schools and adjoining localities and requested to participate in the research program. After obtaining consent, parents were interviewed using a structured format.

RESULTS AND DISCUSSION

Table 1: Comparison of Parental Stress between Mothers of ID Children and Mothers of NID Children

Variable	ID Group(n=120) Mean	SD	NID Group(n=120) Mean	SD	t
Child Domain	131.01	19.81	111.52	17.74	8.03***
Adaptability (AD)	31.19	6.43	27.56	5.81	4.58***
Acceptability (AC)	18.77	5.04	14.25	4.31	7.45***
Demandingness (DE)	25.00	5.36	20.04	4.74	7.59***
Mood(MO)	12.83	3.85	11.02	3.57	3.77***
Distractibility/Hyperactivity (DI)	28.68	4.52	25.97	4.20	4.80***
Reinforces Parent (RE)	14.83	3.63	12.65	3.12	4.29***
Parent Domain	149.33	26.53	120.81	21.14	9.21***
Depression (DP)	26.35	6.03	21.08	5.37	7.15***
Attachment (AT)	16.75	4.19	14.53	3.83	4.20***
Role Restriction (RO)	21.14	5.56	16.62	4.92	6.66***
Competence (CO)	37.52	6.21	29.25	6.66	9.95***
Isolation (IS)	15.41	4.77	13.10	2.98	4.51***
Spouse (SP)	18.42	5.82	14.80	3.97	5.63***
Health (HE)	13.70	3.80	11.37	3.31	5.07***
Total Stress	280.35	42.16	232.34	35.61	9.53***
Life Stress (LS)	16.40	9.16	14.65	7.26	1.64

Table 1 reveals that mothers of children with ID have significantly higher scores on all dimensions of parental stress index except life stress, as compared to mothers of NID.

Table 2: Comparison of Social Support Between Mothers of ID Children And Mothers Of NID Children

	ID Group(n=120)		NID Group(n=120)		
Variable	Mean	SD	Mean	SD	t
Affect	44.20	11.67	40.55	11.39	2.46**
Affirmation	43.88	12.15	38.56	11.38	3.50***
Emotional support	88.09	23.05	79.20	22.23	8.04**
Aid	34.45	10.65	32.10	9.92	1.77
Total functioning	121.74	32.61	111.42	30.17	2.54**
Duration	31.28	8.16	31.76	6.13	.52
Frequency	29.90	7.51	28.05	5.79	2.15*
List	8.60	1.93	8.00	1.84	2.46**
Total network	69.80	15.23	67.82	12.49	1.09
Family support	30.78	12.19	27.03	9.61	2.63***

p<.05p<.01* ****p<.001*

Mothers of children with ID had a significantly higher score on CESD compared to mothers of children of NID Children (M= 19.99, SD=9.60; M=9.75, SD=7.14; T=9.37, p< .001).

DISCUSSION

The findings of the study clearly shows that, overall mothers of children with ID reported higher level of stress and are more depressed than mothers of children without ID. These findings are in agreement with results of earlier studies by Shahida, (2011). This exploratory study was designed to examine the stress faced by mothers of children with intellectual disabilities in Pakistan and the impact of the stress on their family life. One hundred mothers of children with intellectual disabilities in Karachi city, which is in Sindh region of Pakistan, were invited and interviewed. The results indicate that mothers having children with intellectual disabilities face high level of stress due to financial constraints, the inappropriate behavior of the children with intellectual disabilities and lack of resources and therapy facilities for their children. The mothers had symptoms of depression and negative emotional feelings which caused a negative impact on their family life.

Mothers of children with ID reported feeling more depressed and had more difficulties with their sense of competence, more restrictions to the parental role, more strain in their relationship with their spouse and more negative effects on their health. They also rated their children as more distracted, moody, unhappy, and demanding when compared to healthy children.

In another study, poor sleep quality due to parental stress was found in parents caring for children with developmental disabilities by Gallagher et al., (2010). Sixty-seven parents of children with developmental disabilities and 42 parents of typically developing children completed the Pittsburgh Sleep Quality Index, and measures of parental stress, child problem behaviors, and social support. Parents of children with developmental disabilities reported poorer sleep quality. Further, the majority of these parents met the established 'poor sleepers' criterion. The strongest predictor of poor sleep quality was parental stress. This finding withstood adjustment for a number of potential confounded.

Social And Family Support

On the other hand, in terms of social and family support, mothers of ID children had significantly higher emotional support than mothers of children without ID. This may also be a reflection of the fact that even though in India the structure of the family has become nuclear; functionally families still operate within an extended social network. An examination of specific sources of support revealed that mothers of children with ID also relied heavily on healthcare professionals (e.g., speech therapist) than the family and friends to meet their emotional support needs. As noted previously, mothers of children with ID may withdraw from relationship that are stressful or unhelpful, leading to reduced network size, but not overall quality of life received support.

The findings highlight that even though facilities to serve the needs of ID children are increasing, the psychological needs of the mothers remains largely unaddressed. It is of greater concern, since these mothers were selected from facilities where their children were receiving help.

Mothers here have the stress of parenting a young child together with being a co therapist to continue the stimulation of the child at home. If her own emotional needs go unrecognized or unattended, it would negatively impact on the overall outcome. This is an area that merits urgent attention. It not only underscores the need to have more trained professionals to provide both individual and family based psychological interventions, but also highlights the need to sensitize and train other professionals working with children with ID.

CONCLUSION

Half of parents taking care of children with ID experience psychological distress in India. This study encourages health care providers to pay more attention to the mental health of CGs. Further research should examine more detailed information regarding the disease and disability of disabled children, their medical service use, and the quality and quantity of the CGs' social support to improve the method of providing supporting service for both children with disabilities and their families. In our country where we have limited resources and it is high time that we should realize that we may not develop holistic health of the patient if the caregivers are overburdened. So, treatment providers should also shift their focus to the mental health issues of the care givers of ID children.

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Conflict of Interest

The author(s) declared no conflict of interest.

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