

Misinterpretation of Mental Retardation Disability by Caregivers in Jammu Region of India

Dr Shabnum Ravees *, Dr Abhishek Chowhan **

* Assistant Professor, Clinical Psychology, Department of Psychiatry, Government Medical College, Jammu, Jammu & Kashmir.

** Consultant Psychiatrist, Department of Psychiatry, Government Medical College, Jammu, Jammu & Kashmir.

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Abstract- There is abundant research on different areas of Mental Retardation worldwide. The present study intends to assess the misinterpretation among the care-givers of Mentally Retarded patients in Jammu region of Jammu & Kashmir. One hundred fifty-two (152) caregivers who were actively involved in the care of Mentally Retarded patients and reported in psychiatry hospital Jammu for percentage of disability certification for financial/monitory purpose constituted the sample. Caregivers were assessed by a qualitative inquiry by asking the purpose for disability certification and in order to get important information about the MR patient. The patients were assessed on developmental mile stone Screening test, Bhatia Battery performance test of intelligence, Seguin Form board test. Caregivers of patients with severe, profound and major psychiatric illness were excluded from the present study. The study showed that mental retardation disability and financial benefits to the intellectually disabled are considered as a sort of nail in the coffin for such patients and no further attempts are made to rehabilitate the disabled person. The patient is considered as a financial burden. The authors insist on better psychosocial rehabilitation services in addition to the financial benefits to the disabled persons.

Index Terms- Misinterpretation, Disability of Mental Retardation, disability pension, financial benefits

I. INTRODUCTION

Mental retardation (MR) or intellectual disability is defined as limitations in an individual's intellectual and adaptive functioning. The term was once used only to denote cognitive difficulties but the concept was rightly broadened to include an individual's functioning and interaction with the environment. The Mentally Retarded individual has lack of ability to generalize information from one situation to another and often finds it difficult to use his executive controls. Such individuals have significantly below average mental functioning with intelligence quotient or IQ of 70 or less as compared to the normal average of 100. Such limitations cause problems with everyday living. People who are mentally retarded may have problems with communication, taking care of themselves, daily living, social skills, community interaction, directing themselves, health & safety, school, ledger activities and work. This condition is more common in boys than girls. This is assumed to be due to mutations

on the X chromosome (Raymond FL, 2006). Mental retardation may begin at birth or in childhood.

There are four levels of mental retardations. Mild, Moderate, Severe, and profound. These levels are determined by performance on standardized IQ tests and by the potential to learn adaptive skills such as communication and social interaction. Children with IQ level between 55-69 are diagnosed as mild mental retardation. These often go undiagnosed until they are well into their school years. They are often slower to walk, talk and feed themselves than most other children. They can learn practical skills, including reading and math, upto about 4th to 6th grade level. Mildly retarded adults usually build social and job skills and can live on their own. Moderate mental retardation people have IQ ranging from 40-54. Children who are moderately retarded show noticeable delays in developing speech and motor skills. Although they are unlikely to acquire useful academic skills, they can learn basic communication, some health and safety habits, and other simple skills. They cannot live alone usually but they can do some simple tasks and travel alone in familiar places. People have IQ's ranging from 20-39 and are considered severely mentally retarded. Their condition is likely to be diagnosed at birth or soon after. By preschool age, they show delays in motor development and little or no ability to communicate. They usually learn to walk and gain basic understanding of speech as they get older and they need to be directed and live in a protected environment. Children with IQ of 0-24 are considered profoundly retarded. Their condition is usually diagnosed at birth, and they may have other medical problems and need nursing care with training, they may learn to use their legs hands and jaws. They cannot take care of themselves and need complete support in daily living.

Mental Retardation may be caused by many factors. However, etiologically this may be put under three broad categories: Primary, Secondary and Cultural familial. Primary Mental Retardation is a chronic state of sub-average intelligence, caused by congenital malformations and do not show much improvement in spite of intensive remedial training. Secondary Retardation is caused by localized brain damage or physiological disorders affecting intellectual processes involved in learning leading to significant deterioration of intelligence and adaptive behavior. An individual with secondary retardation may show variable pattern of skills. In some cases, there may be dramatic improvement in IQ after Training. The third type of retardation is caused by Psychosocial or Cultural deprivation. This group is most responsive to remedial education, rehabilitation and training.

If a person's performance or social functioning is inadequate or affected, it may lead to greater burden on the care-givers. In such situations, the occurrence of disorder in the family is perceived as a trauma. The field of disability has attracted substantial scientific attention and public concern in recent times, which is in sharp contrast to the situation that existed in last few decades. Major changes have occurred in the immediate socio-political environment and has influenced our contemporary understand of the nature of the disability. Most prominent among the events are enactment of the persons with disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 which has been replaced recently by Rights of Persons with Disability act 2016 (The rights of persons with disabilities act, 2016), establishment of the Rehabilitation Council of India and National Institutes devoted to the welfare of people with different disabilities. The persons with disability (PwD) act provide for welfare benefits for persons with various disabilities including mental disability. These benefits include disability pension, travel benefits, insurance schemes, reservation in employment & education, IT exemptions, loans, skill training & job placements, housing schemes, marriage allowance, pension transfer to PwD, exemptions from routine transfers and free legal aid services (Hamza A (Ed), 2014). Not taking anything away from these prodigious aids to a population really in need of such services, sometimes mistakenly these are considered as alms for a unimprovable illness by the caregivers. They begin to think that a disability pension means that person with the illness can't get better now and they stop seeking help for psychological and vocational betterment of the person.

If a person's performance or social functioning is insufficient, it may lead to more stress and distress to the family members. Provencher (1996) found that the negative consequences identified most frequently were tense relationships in the household, physical and emotional problems of the primary caregivers, disturbance of the lives of other adults in the household and disturbance in the primary caregiver's work performance. Most carers reported personal and social restrictions, but carers were significantly more likely than non carers to report financial, personal and physical burden (McGilloway et al, 1997). This chronic stress and social description and narratives of mental retardation produces a sense of rejection and dejection in caregivers. They sense to feel that now they are stuck with a disease where no treatment is possible and solely begin to focus on the financial aspects of the disability certification. This attitude leads to colonial mindsets where individuals with MR were generally isolated, rather than encouraged to lead fulfilling and healthy lives. Therefore, the present study was carried out with aim to bring substantial change in the perception of caregivers for disabled persons with regard to social skills training, self-management, rehabilitation and special education.

Objective:-

- To study the effects of education of care givers on treatment modalities
- To study the effect of socio-economic status on treatment modalities.
- To examine the influence of age on treatment modalities

II. MATERIALS AND METHODS

The present study sample comprised 93 males 59 female caregivers of Mentally Retarded patients reported to Psychiatric Disease hospital Jammu from September 2010 to 2014 September reported for certification of disability through the district disability boards. The district disability board in J&K is headed by the chief medical officer of the respective districts. In this study the term caregiver was used to refer to a person above 16 years of age, male or females, who is actively involved in the care of patients in same house for not less than 10 years. Caregivers with IQ less than 70 and those who did not consent were excluded from the present study. In addition, caregivers of patients with Severe, profound and major psychiatric illness were excluded from the present study.

Tools:-

1. Developmental mile stone Screening test-DST (Bharat Raj J, 1983) is a non-verbal test to measure the mental development of children from birth to 15 years.
2. Seguin Form Board Test is the most commonly used performance test used as a quick measure of general intelligence in children between 3 to 11 years and for Mentally Retarded adults.
3. Bhatia Battery performance test (Bhatia CM, 1955) consists of five sub-test for measuring the intelligence between the age group of 11yrs-16 yrs and for both illiterates and literates.

Procedure:- The assessment were carried out on the selected sample of 152 children where the tests were individually administered, with instructions about the tests in order to assess the degree of Mental Retardation. The test took 1 to 2 hours to administer on every patient. After testing each patient was scored for each scale following the respective standard procedure for scoring. A Qualitative inquiry was sought from caretakers by asking the purpose for applying of disability certificate asking one question "Aap ko ye disability certificate kyun chahiye", (Why do you need disability certificate?). The qualitative inquiry was to enable the care givers to "Articulate" their history about the child personal way. A semi structured interview for care givers was framed in order to get important information about child. Based on caregiver's demographic information, Age, education level, occupational status, socio-economic status, marital status, religiosity, area of residence (rural or urban) and siblings order. Data obtained on demographic were analyzed by Percentage method.

III. RESULTS

The present study revealed that the caregivers/parents who reported for disability certification were Middle to Old age. The age ranged from 40 years to 60 years. Among those majority of the caregivers were illiterate. Because of academic deficits, the cognitive mechanisms involved by caregivers for their patients were very poor in respect of any rehabilitation program to live with dignity. Majority of the caregivers were parents of the patients. Table 1 shows the socio-demographic profile of the caregivers.

Socio-demographic characteristics of the sample: - Caregivers=(N 152)

S.no	Variables	N	Percentage (%)
1.)	<u>Age:</u>	152	
	40 to 60 years	144	94.74%
2.)	<u>Sex</u>	152	
	Male	93	61.18%
	Female	59	38.81%
3.)	<u>Education:</u>	152	
	Literate Up Graduate	6	4 %
	Illiterate	146	96 %
4.)	<u>Socio-Economic status:</u>	152	
	Lower	132	87%
	Middle	18	13.15%
	Higher	2	13.31%
5.)	<u>Occupation:</u>	152	
	Farmers	62	41%
	State employee	14	9.21 %
	Workers	76	50%
6.)	<u>Habitat:</u>	152	
	Rural	107	70.39%
	Urban	45	29.60%
7.)	<u>Marital Status:</u>	152	
	Parents	112	74%
	Single close relation	2	1.31 %
	Widows	34	22.36%
	Divorced	4	2.63%
8.)	<u>Religion :</u>		

	Hindu	110	72.36%
	Muslim	13	8.55%
	Sikh	28	18.42%
	Christian	1	0.65%
9.)	<u>Sibling order :</u>		
	1 st child	53	34.86%
	2 nd child	35	23.02%
	3 rd child	30	19.73%
	4 th child	23	15.13%
	5 th child	5	3.28%
	6 th child	1	0.65%
	7 th child	3	1.97%
	8 th child	2	1.3%
10.)	Level of Mental Retardation	152	
	Mild Mental Retardation	64	42.1%
	Moderate mental retardation	88	57.9%

IV. DISCUSSION

The main objective of the present study was to bring substantial changes in the lives of disable persons through their caregivers. One of the major problems faced by the caregivers was negative and ill-informed attitude towards Mental Retardation that they are unable to do anything work. Very few were educated up to graduate, their main concern was financial burden as who would look after the patient when they are no more and their savings were drained because of regular expenses of the chronic disorder. Karp (2001) in his study found that financial stress / burden stems not only from actual expenses of care giving like medication but financial strain also occur from “*opportunity cost of care*” the things someone gives up to become a care giver for example quits job or declines job promotion or advancement opportunities. The present study revealed that majority of the reported in hospital were from Weaker / Poorer sections of the society in Rural areas; as also reported in National Sample Survey Organization that the incidence of disability was more in Weaker / Poorer sections of Rural areas. This is because in rural areas facilities for optimal training in social skills are not available. Services like village level workers equipped with skill in home training for Mentally Retarded persons are lacking in most rural areas.

On analysis tense relationship among the parents as care givers were reported. Widows & divorced caregivers also contributed to the sample. Two participants were from close relationship from maternal house and were living together from more than 10 years. Province (1996) found that the most negative consequences of care giving was tense relationships in the household and also disturbed work performance. Further, the caregivers reported that they found undefined and stressful nature of the care giving role as there are few guidelines available. This undefined role was also reported in a study conducted by Deimling and Bass (1986). It is noteworthy that the two care givers who were from close-relation could understand the nature of disability and change the mind set about disability and bring substantial changes through training as a caregiver. These major changes include special education and self-management for patient which could improve the family members daily living conditions as well as reduce care giving stress. Most of the caregivers were from Hindu families, followed by Sikh and Muslim, and one from Christian family. It was noticed that degree of burden with respect to finance was main concern for all caregivers, as to who will look after patient when they are no more. This was seen in all the religious communities. Most of the caregivers reported embarrassment, anger and helplessness in case their child behaved in a socially unacceptable way. This helplessness turned into

dejection and would force them think that no permanent and effective treatment is possibly for this issue. Academic deficits, low level of cognitive maturity, lack of professional health care, few social guidelines for caregivers and low socio-economic status made caregivers feel that patient is unable to perform any work. It is clear from the caregivers that they faced many problems while caring for a Mentally Retarded person. Their social and personal life was affected, while dealing with social unacceptable behavior of the patient. Moreover, the patient was dependent on the care givers who were older and their major concern was who would look after patient when they are no more which is basically dominated by the fact that they take responsibility for their Mentally Retarded child.

Of all the participants in the study only two turned up for follow up after being called for psychological treatment of their mentally retarded children. They were educated how things work for these children. Like how positive changes can be brought in patient through social skill training, special education and self-management. In order to justify above mentioned findings of the study it was found that all care givers of Mentally Retarded patients carry very similar psychological burden and are exposed to similar situational stressors which was supported by Sinha (2013) that all primary care givers share similar fate in their life, which is basically dominated by the fact that they take responsibility for their mentally ill family member. The feelings of isolation and stigma as well as restrictions in social activities where common experience of care givers. Similar findings have been reported in a number of studies (Grad & Sainsbug 1963, Mandelbrot & Folkard 1961, Waters & North 1965, Winefield & Harvey 1994). The degree of burden experienced is influenced by patient caregivers related factors and also varies by age & gender, and greater burden is associated in older care givers.

V. CONCLUSION

Our study in no way tries even a little bit to belittle the disability pension given to the persons suffering from an illness as disabling as Mental Retardation. However, our endeavor is just to bring into light the mentality of society in general and caregivers in particular regarding the monetary benefits associated with disability pension. Based on the findings of present study, which is first of such kind of research in Jammu region, one of the major problems noticed by researcher was negative and ill-informed attitude due to lack of scientific knowledge and exposure in the field of mental retardation among the care givers. The patient illness was considered as burden in terms of finance by care givers and feels who will look after them when they are no more. And hence disability is applied to take care of the financial inadequacy of the person with mental retardation and very little effort is then made to rehabilitate the intellectually disabled. The researcher emphasizes on participation of caregivers for improving the life of disabled peoples not only through financial benefit but also to make them understand about the self-management, social skill training and special education for mild and moderate mentally retarded children. There is need of administration to understand and to give professional training and provide better developing facilities at both primary and tertiary level. An important finding was non-availability of professional help especially occupational and vocational training. Emphasis should be on workshop and

orientation programs for care givers. Therefore, there is a need for producing better rehabilitation procedures available for people with Mental Retardation, so that they will feel how things work in the real world. (Malhotra 2011)

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AUTHORS

First Author – Dr Shabnum Ravees, Assistant Professor, Clinical Psychology, Department of Psychiatry, Government Medical College, Jammu, Jammu & Kashmir.

Second Author – Dr Abhishek Chowhan, Consultant Psychiatrist, Department of Psychiatry, Government Medical College, Jammu, Jammu & Kashmir.

Correspondence Author – Dr Abhishek Chowhan, Consultant Psychiatrist, Department of Psychiatry, Government Medical College, Jammu, Jammu & Kashmir. E-Mail: abhi3212007@gmail.com, Mob: 8803838383

