

Awareness on different aspects of Intellectual Disability among caregivers

Sunita Purty*

Amool R Singh**

ABSTRACT

There are increasing numbers of children being diagnosed with intellectual disability. Social, cultural and educational components in the society are helping to increase awareness about this disability, subsequently to diagnosis, its acceptance by the affected family too. Caregivers need to identify the problem, obtain evaluation and handle the situation in such way that the intellectually disabled child as well as his family could be help to adjust properly in the society, and make optimum use of their abilities. The current study was undertaken to find out the awareness on different aspects of intellectual disability among caregivers having children with intellectual disability. Sample of the study consists of 100 caregivers having children with intellectual disability were, chosen by using purposive sampling technique. GHQ-12 and NIMH, GEM Questionnaire (Reeta Peshawaria et al., 2000) was used to assess the knowledge and awareness about intellectual disability among caregivers, after fulfilling the inclusion criteria. This was a cross sectional study conducted at Ranchi Institute of Neuro-Psychiatry and Allied Sciences (RINPAS) Kanke, Ranchi India. Result showed that less educated caregivers had high misconception regarding all the three areas of awareness than caregivers who were educated up to matriculation or above. Further result showed that the caregivers hailing from rural area had more misconception about etiology and management factors related to intellectual disability.

Keywords: Intellectual Disability, Awareness

* Sunita Purty, Assistant Professor, Dept. of Clinical Psychology, PGIBAMS, Raipur (C.G.)

** Amool R Singh, Professor, Dept. of Clinical Psychology, RINPAS, Ranchi (Jharkhand)

Introduction

Parents or caregiver are the primary caregiving resources for the children with or without any kind of disability. They are the managers, behaviour models, disciplinarians and agents of socialization and change for their children. Studies shows that they often lack the knowledge and skill needed to assists their child because of their lack of awareness or misconception about the problem which his/her child suffering from. Thus if the parents are adequately given information or trained they can be a better teacher or trainer of their disabled children. Keeping in this view awareness regarding various aspect related to children with intellectual disability in their caregiver was tried to investigated in this study.

Intellectual disability is not always defined in the same way across research studies or service agencies, even within the same state (Koller et al., 1984; Borthwick-Duffy, 1994). While some definitions rely on IQ scores alone to classify individuals with MR, some only use adaptive behaviours for classification, and others include both IQ scores and measures of adaptive skills (Whitman et al., 1990; Borthwick-Duffy, 1994). The American Association on Intellectual and Developmental Disabilities (AAIDD, 2002) has defined MR as significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18. Intellectual limitations refer to an Intelligence Quotient (IQ) which falls two standard deviations below the population mean of 100 (<70), and adaptive functioning limitations refer to impairments in at least two out of ten skill areas (AAMR, 2000).

According to the tenth revision of the WHO (World Health Organization): Intellectual disability (ID) is a disorder defined by the presence of incomplete or arrested mental development, principally characterized by the deterioration of concrete functions at each stage of development and that contribute to the overall level of intelligence, such as cognitive, language, motor and socialization functions; in this anomaly, adaptation to the environment is always affected. For ID, scores for intellectual development levels must be determined based on all of the available information, including clinical signs, adaptive behavior in the cultural medium of the individual and psychometric findings.

Family/ Caregivers perspectives and Awareness towards child's problem:

All parents expect to be gratified by their children and hope that they will be intelligent, brilliant students, triumphant and, subconsciously, expect then to become a second, corrected and better version of themselves. Nevertheless, upon confirmation of the diagnosis, their expectations are destroyed becoming overwhelmed by a sense of loss, not to mention the obligation of having an unwanted child. This news often provokes feelings of guilt in the parents and outright aggression between them, in addition to hostile reactions toward the doctor; consequently, it is necessary to be prepared and to provide the support needed. The initial reaction is denial. Then, during the first years, the parents justify the discrepancies during the critical development periods while becoming more demanding as the child grows up, without results. The impossibility of attaining the expected goals generates a great deal of frustration and can lead to serious errors in childrearing, which without doubt, significantly affects the psychological development of these children. As a result, parents must face the correct diagnosis so as to minimize the denial mechanism (among other issues that will be described later). A great deal of empathy is required on the part of the doctor when reporting the diagnosis. Parents need to perceive security and confidence from health professionals; know that they will not face the problem alone and that they will receive guidance throughout the long and arduous path. If the deficit is notable, the diagnosis can be made earlier, but the effect is more devastating. It is necessary, therefore, to

provide support for accepting the diagnosis; only in this way can the search for “magic cures” brought on by pain and denial be avoided. This not only provokes catastrophic expenses but also extremely traumatic experiences; each time, the failures become evident. When there is organic evidence, the initial diagnosis and the need to confront the parents almost always falls on the gynecologists or pediatricians (neonatologists). If a moderate or mild mental disability is involved, the diagnosis is generally established by personnel in the field of education. A referral to a doctor is recommended only if an incorrect diagnosis is established, if behavioral problems are present or if the family requires guidance. On occasion, when a diagnosis is determined by the educational institution, a doctor will be consulted to corroborate the diagnosis or to advise the parents as to treatment for behavioral disorders that prevent the child’s normal development in school or at home.

The first and most important is the parents acceptance of their children’s limitations and the impossibility of attaining “normality.” After this, the age upon beginning the rehabilitation program should be considered as well as obtaining a level of continual productivity that is consistent with the disability, the existence of a group to which to belong and, lastly, the unconditional affection of the parents. It has been stated that the above mentioned factors reduce psychiatric comorbidities (depression, anxiety, behavior) and a prevalence equal to that of the non-disabled population is found. Intellectual disability is not curable; and yet, the prognosis in general terms is good when using the emotional wellbeing of the individual as a parameter. When the parents are asked, after they have accepted the diagnosis, they express their long-term expectation, that ‘their children be happy’ or that ‘they be self-sufficient’ that is, to see them content and self-sufficient compensates for the lost hope of having a professional child or one that satisfies the parents’ unfulfilled dreams’. This is a striking contrast with parents who reject the disability and for whom the only acceptable parameter is “normality.” Of course, in these cases, the patients not only suffer more but the parents also live in constant agony.

The role of family and caregivers is crucial. They are an important source of information, as they are in a unique position to observe changes in the child's behaviour and how they may be related to environmental influences. They also play an important role in implementing and monitoring treatment (MENCAP, 2004). If such knowledge and skills are absent, the health needs of children with intellectual disability may remain unmet and there may be unnecessary referrals to secondary or tertiary services because primary health care workers are not comfortable treating children with disabilities within the primary health care system. It is crucial that communication with caregivers be fostered and their views respected.

Review of Literatures:

Very few researches were found in the area of awareness among parents regarding knowledge and information about intellectual disability. However many areas have been touched e.g. burden of the caregivers, stress, coping strategies among parents etc. Study conducted by Goswami (2013) which was a survey study in the family of children with intellectual disability (ID). Study finding indicates the parents were seen to be over protective in nature. In that case it was considered as a negative parental attitude expressed towards them, in the field of psychiatry. It was also found that parents withdraw from the society due to insulting and unpleasant comments made by the so called well-wishers regarding their differently able child and which were not like the comments made to their normal counterparts. Again it was seen that, at the back of the mind, of those parents of the ID children, that their expectations regarding their children would never be fulfilled. The frustrations resulting in the un-fulfillment of their expectations was due to the

demolition of expectancies rather than being disabled. From this study it was observed that many of them do not have any care save their own mothers. One of the significant findings was that the parents were usually worried about their child's future. Again the researcher found that the parents were not in a usual habit to save money for their child with ID, which makes their future much more insecure.

Another study done by Shetty & Menezes (2013) which aimed to assess the knowledge of the parents regarding the intellectual disability, psycho-social, economic problems they face. The study included 50 parents of mentally challenged children in Mangalore district. Result revealed that fifty percent respondents from rural area believed that it was the evil eye that has caused their child to develop this condition and 16.67% felt that it was the condition which the child developed during the pregnancy of mother some of them felt, since they were educated that this has resulted when the fetus did not develop properly during pregnancy and 5.56% felt that it is hereditary that is the genetic conditions sometimes it is caused by abnormal genes inherited from parents and 27.77% rural people felt that is the injury during birth for this condition. In rural set up the 54.45% respondents said that they felt bad in the company of ID child to go for social gatherings or get together. In a semi urban set up 60.57% respondents perceived that they found difficult to go out for social interaction or for family leisure outside having the retarded child and 45.45% from urban set up felt that they feel going out with a retarded child. They felt that their social status is affected much by taking the child out when compared with a normal child. But the other respondents from urban and semi urban, 54.45% from urban and 39.43% from semi urban felt that their life is not affected at all with the presence of the mentally retarded child in the family.

Aim: The study was undertaken to find out the awareness on different aspects of intellectual disability among caregivers.

Research design: This was a hospital based cross sectional study. The subjects were recruited for the study by purposive sampling technique.

Sample of the study consists of 100 participants or caregivers having children with intellectual disability.

Hypothesis: Awareness regarding intellectual disability will be present in caregivers of children with intellectual disability.

Inclusion and Exclusion for the caregivers

Inclusion criteria: Educated up to at least 5th std., Age range 20-50 years, Care giver should know the child since 5 five years, Co-operative for the study, They should comprehend the test instructions.

Exclusion criteria: History of intellectual disability, History of any Physical or Psychiatric illness, Unable to come at follow up sessions.

Tools used:

Socio Demographic and Clinical Data Sheet: A socio-demographic data sheet was prepared for the present study. It consists of socio-demographic characteristics of age, education, sex, occupation, domicile, religion, past history and family history of mental illness and physical illness, duration of illness etc. of the children and their caregivers too. The checklist was administered on the caregivers of the individuals with intellectual disability. It aims at measuring

the awareness among caregivers of intellectual disabled individual regarding causes, treatment etc.

General Health Questionnaire-12 (GHQ-12): The psychological health of the caregivers was measured using the 12-item General Health Questionnaire (GHQ-12) (Goldberg & Hillier, 1979). It is a self-report questionnaire to measure of current mental health, it focus on two major areas the inability to carry out normal function and the appearance of new and distressing experience. The items are scored as 0 to 1. The GHQ is a screening tool which was used to identify the severity of psychological distress experienced by an individual within the past few weeks.

NIMH GEM Questionnaire: This test was developed by Reeta Peshawaria et al. (2000). The test measures the level of awareness among parents, family members and general public towards the condition to mental retardation. It has 30 items divided into 3 sections namely 11 items of general information (G), 9 items of etiology (E) and 10 items of management (M). The items are stated in the form of a statement and the respondent is expected to indicate whether he/ she agrees with the statement or not. Each statement is given a score of 1, given to the direction of misconception; high score indicates higher the misconception regarding the mental retardation. This test was found significant with high reliability and validity. Split half reliability for this test using Spearman Brown Prophecy formula after correction was observed to be 0.66. Test retest reliability was found to be 0.86.

Procedure

In this study caregivers (N=100) who accompanied their child to the OPD and fulfilling inclusion criteria were selected from outpatient department of Ranchi Institute of Neuro-Psychiatry and Allied Sciences (RINPAS), Kanke, Ranchi, India. Participants whose caregivers were able to give consent to participate in the study were selected for the study. Necessary socio-demographic details were collected. GHQ -12 was administered for screening purpose to identify the psychological health of the caregivers. Then Awareness regarding intellectual disability among caregivers was assessed by administering NIMH GEM Questionnaire. After assessment family counseling regarding intellectual disability to the care givers was done, in which they were informed about cause, prevalence, factors like influence of family environment to the child problem, sibling, peer-group, genetic counseling, institutional counseling, and prognostic guidelines was focused.

Statistical analysis:

The obtained data was analyzed by using the computer software program, Statistical Packed for Social Sciences version 16.0 (SPSS-16.0). Mean, Standard Deviation, t- test, and ANOVA were used to analyze the data. Results are summarized in the following table given below.

Table 1: showing mean age of the caregivers

variable	Mean	SD
Age of caregivers	38.70	8.94

Table: 1 shows mean age of the caregivers of children with intellectual disability. The average mean score of 100 caregivers was found 38.70 ± 8.94 .

Table 2: Comparison of awareness among caregivers (father, mother and others) on NIMH GEM Questionnaire

Misconceptions	Mother (N=49)	Father (N=45)	Others (N=6)	df	F
	Mean ± SD	Mean ± SD	Mean ± SD		
MGI	3.61±1.79	3.47±1.90	2.33±1.75	2	1.29 ^{NS}
ME	1.80±1.63	2.27±1.80	2.50±2.26	2	1.06 ^{NS}
MM	1.84±1.40	1.58±1.74	2.33±2.07	2	0.729 ^{NS}

MGI- Misconception on general information, ME- Misconception on etiology, MM- Misconception about management, NS- not significant

Table 2 shows the awareness among caregivers (mother, father and other caregivers). Result table clearly indicates that there were no differences found among all the three types of caregivers included in the study. They have the same information regarding the misconception about general information, etiology and management about children with intellectual disability.

Table 3: Comparison of awareness among caregivers in regards with education variable (below matric and studied up to matric or above)

Misconceptions	Below matric (N=53)	Matric or above (N=47)	df	t
	Mean ± SD	Mean ± SD		
MGI	3.85±1.736	3.04±1.89	98	2.225*
ME	2.74±1.77	1.28±1.38	98	4.563**
MM	2.23±1.69	1.21±1.30	98	3.323**

*Significant at 0.05 level, **Significant at 0.01 level

Result (table-3) reveals those caregivers who were educated below matriculation had higher misconception regarding all the three areas of awareness in the comparison of caregivers who were studied up to matriculation or above. The difference was found statistically significant on all the three (general information, etiology and management) dimension of awareness scale.

Table 4: Comparison of awareness among caregivers belonging from Rural and Urban area

Misconceptions	Rural (N=54)	Urban (N=46)	df	t
	Mean ± SD	Mean ± SD		
MGI	3.80±1.93	3.09±1.68	98	1.943 ^{NS}
ME	2.67±1.69	1.33±1.54	98	4.117**
MM	2.26±1.70	1.15±1.25	98	3.663**

** Significant at 0.01 level.

It is clear from the table (4) that caregivers who were from rural area had more misconception about etiology and management factors related to intellectual disability. However in the area of general information there were no significant difference found in the caregiver belongs to rural or urban area.

Discussion and Conclusion:

The present study was undertaken to investigate the awareness on different aspect in the caregivers of children having intellectual disability. In the sample of 100, the children having mild level of intellectual disability were 29%, 39% were at moderate level and 32% children were having severe level of intellectual disability (not shown in results). Most of the caregivers have mean age of 38.70 ± 8.94 .

Result reveals that caregiver who had education below matriculation had higher misconception regarding all the three areas of awareness in the comparison of caregivers who had studied up to matriculation or above. The difference was found statistically significant on all the three (general information, etiology and management) areas of awareness. Further the result shows that caregivers residing from rural area had more misconception about etiology and management factors related to intellectual disability. However in the area of general information, no significant difference found in the caregiver belongs to rural or urban area.

In the area of misconception about general information, caregivers below the matriculation believed that 'Mental retardation is an infectious disease', 'mental retardation is mental illness', 'as the mentally retarded child grows up he would gradually become normal'. In the etiological factors caregivers had misconception that 'Mental retardation is due to fate or karma'. 'A mentally retarded child is born due to the sins of parents'. They also believe that 'Mental retardation is due to black magic or spells'. Most of them also agreed on 'Mental retardation is caused as an effect of lunar eclipse at the time of pregnancy or birth of the child'. In the management area caregivers reported that 'mental retarded person can be fully cured', 'Traditional healers, poojaries can cure mentally retarded person' they also had misconception that 'A mentally retarded individual can become as capable as a normal individual'.

Present study finding is supported by study conducted by Shetty&Menezes (2013) in which they reported that 50% respondents (parents) from rural area believe that it is evil eye that has caused their child to develop this condition. They also mentioned that uneducated parents of ID had not having any knowledge of retardation. Another study done by Vijayarani et al. (2016), reported that 78% of the family caregivers had inadequate knowledge in the care of mentally challenged children. However in the present study no significant difference was found among, mother and father and other caregivers in any area of awareness, which indicates they (mother, father and other caregivers) had similar misconception about intellectual disability.

Limitations of the study:

- Depth study with accuracy was constrained due to resources and other factors e.g. OPD settings, patients coming from far distance, severity of the child's problem etc.
- The study was done in a hospital setting only, where caregivers accompanied the child but other caregivers having children with same problem who were unable to reach the hospital due to lack of information or another reason could not be assessed.

Clinical Implications:

Increasing number of children with intellectual disability in hospitals indicates that now changes occurring in parental awareness as well as attitude regarding their disabled child make them to visit hospital. But still they are not that much aware about intellectual disability, they need to know more details about intellectual disability for the betterment of their child. Thus if they can be provided information regarding the different aspects or issues related to their special child, they can make their child's life easier as well as their own at the other hand. At the same time intervention strategies as well as awareness program could be implemented in the community setting.

References:

- American Association on Intellectual and Developmental Disabilities. (2002). *Mental Retardation: Definition, Classification and Systems of Supports* 10th ed. Washington DC: AAIDD.
- American Association on Mental Retardation. (2000). Retrieved at: <http://www.AAMR.org>. May, 2000.
- American Psychological Association. (2010). *Publication manual of the American Psychological Association* (6th ed.). Washington, DC: Author.
- Borthwick-Duffy, S. A. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical Psychology*, 62, 17–27.
- Goldberg, D. P., & Hillier, V. F. (1979). A scaled version of the General Health Questionnaire. *Psychological medicine*, 9(01), 139-145.
- Goswami, S. (2013). The Parental Attitude of Mentally Retarded Children. *Global Journal of Human Social Science*, 13, 1-11.
- Koller, H., Richardson, S.A. & Katz, M. (1984). The prevalence of mild mental retardation in the adult years. *Journal of Mental Deficiency Research*, 28, 101- 107.
- MENCAP (2004) *Advocacy Strategy: Mencap's Three Year Plan for Supporting People with a Learning Disability to Speak Up for Themselves*. London: Mencap.
- Reeta Peshawaria, D.K. Menon, Loraine Stephenson (2000). NIMH GEM Questionnaire. National Institute for the Mentally Handicapped. Manovikasnagar, Hyderabad, India
- Shetty L & Menezes S. (2013). A study on the problems faced by the parents in handling the mentally challenged children in mangalore district. *Global Journal of Interdisciplinary Social Science*, 2, 1-5.
- Vijayarani, M., Balamurgan, G. and Kasthuri, G. (2016). Knowledge of family caregivers on care of mentally challenged children at selected institution, Bangalore: A descriptive study *International Journal of Applied Research* 2016; 2(8): 808-812.
- Whitman TL, Hantula DA, Spence BH. (1990). Current Issues in behavior modification with mentally retarded persons. In Matson JL (ed) *Handbook of Behavior Modification with the Mentally Retarded*. New York: Plenum Press.
- World Health Organization (1960) *Epidemiology of mental disorders*. Technical Report Series No. 185.
- World Health Organization (1992) *Tenth Revision of the International Classification of Diseases and Related Health Problems (ICD–10)*. Geneva: WHO.