



Parental Wellbeing and Clinical Characteristics of Children with Intellectual Disability

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ABSTRACT: This study aimed to see the psychological well-being of the caregivers and its relationship with the clinical characteristics of children with Intellectual Disability (ID).

Methods: A total of 20 caregivers of children with intellectual disability were purposively selected from Central Institute of Psychiatry and Deepshika Institute of Child Development and Mental Health, Ranchi. Socio-demographic and clinical data of caregivers and their children with intellectual disability was collected using specially designed clinical datasheet. The caregivers were assessed with General Health Questionnaire-28 (GHQ-28), Ryff's Psychological wellbeing scale, Family Interview for Stress and Coping in Mental Retardation (FISC-MR), Social Problem-Solving Inventory (SPSI-R) and Self-determination scale (SDS). Intelligence quotient of the child was assessed with the average score of VSMS and DST and percentage of disability using Assessment of Disability in Persons with Mental Retardation (ADPMR).

Results & Conclusions: Study identified a significant relationship in the caregiver's psychological well-being associated with the clinical characteristics of children with intellectual disability. There is decreased psychological wellbeing in the caregivers and is related to the clinical characteristics of the children with intellectual disability.

There are very few culturally sensitive parent intervention practices directed to the key caregivers of children with intellectual disability and that these practices should be enhanced.

Keywords: Key caregivers, Children with intellectual disability, Psychological wellbeing



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1. INTRODUCTION

Parents' foremost reaction to the birth of a child with an Intellectual Disability (ID) is often a blend of ineptness, loss, and resentment leading to decreased psychological wellbeing. The adjustment process for parents is often more difficult as additional demands may be placed on parents. Studies have shown that parents of children with intellectual disability report experiencing greater stress than parents of children without disabilities (Olsson & Hwang, 2001; Gupta & Kaur, 2010). The child with an intellectual disability may need hospitalization, developmental services, medical care, and basic caregiving services beyond those of a typically developing child. These demands can be continued for parents as they deal with time constraints, financial demands, intense emotions, and feelings of scantiness about their ability to adjust to their child's needs.

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Various characteristics of children with intellectual disability have been found to affect the levels of stress that their parent's experience. The severity of the child's intellectual impairment, the age of a child found to predict the parental stress levels. When the child enters school, more time and effort is needed on the part of the parent to help the child be successful. As the child gets older, parents may not have access to information on how to cope with older children with intellectual disability (Wikler, Wasow, & Hatfield, 1981). While several child factors can contribute to the increased level of stress experienced by parents of children with intellectual disability, the severity of the child's behavioral problems is one of the strongest predictors of parental stress (Nachshen, Garcin, & Minnes, 2005). Even though there were many studies portrayed the parental wellbeing, there were fewer studies focusing the relationship of the child characteristics (i.e., IQ level of the child and disability level) with the wellbeing of the caregivers. Thus, conducted the study to find out how the clinical characteristic of the children with intellectual disability is associated with the psychological wellbeing of their caregivers.

2. Method

This study was conducted at Central Institute of Psychiatry and in Deepshika Institute, Ranchi; Jharkhand. Total of 20 samples was selected through purposive sampling technique. The samples of the study were one key caregiver of each 20 children with intellectual disability. Fifteen key caregivers of children with intellectual disability were selected from the Erna Hoch Centre for Child and Adolescent Psychiatry of Central Institute of Psychiatry and remaining five key Caregivers were taken from the Deepshika Institute for Child Development and Mental Health, Ranchi. The children were clinically assessed using clinical data sheet and were diagnosed by the International Classification of Disease- 10th Revision- Diagnostic Criteria for Research, (ICD-10- DCR). Socio-demographic and clinical data were collected with specially designed Performa and level of disability in the child using Assessment of Disability in Persons with Mental Retardation (ADPMR). The intelligence level of the child was assessed by the clinical psychologist of the institute, and the score was recorded. Caregivers were assessed with General Health Questionnaire-28 (GHQ-28), Ryff's Psychological wellbeing 42 item scale, Family Interview for Stress and Coping in Mental Retardation (FISC-MR), Social Problem-Solving Inventory-Revised scale (SPSI-R), and Self-determination scale (SDS) by Sheldon & Deci.

3. Results

3.1 Socio-demographic profile of the children with intellectual disability and their caregivers

Out of the total population; more than half of the children were males (65%), most of them (n=13) has one sibling, and 60% of them are first born. Only one belongs to scheduled caste/tribe, and half of them (50%) belong to other backward castes. One of them was from other religion, and the remaining (95%) were Hindus. More than half (n=13) were from the rural area and was from joint family (65%). The majority (85%) of the fathers were self-employed, and the remaining 15% were in government service. Almost all the mothers (95%) were housewives. Majority of the family (75%) belongs to lower socioeconomic status and majority (85%) of the mothers were caring their children with intellectual disability.

The average age of children with intellectual disability was 10.05 ± 4.57 years. Average ages of father and mother were 37.85 ± 5.54 and 32.40 ± 5.41 years respectively. Average father's education was 11.10 ± 3.86 years, and mothers were 10.30 ± 4.29 years. Average monthly income of them was Rupees 15300.00 ± 10498.62 .

3.2 Clinical profile of the children with intellectual disability

Out of 20, seventy percent of the children were born out of normal vaginal delivery, and 30% had cesarean section. Almost half of the children (45%) had delayed birth cry, and 40% of them had the presence of serious medical illness during infancy/childhood. Most of the children (65%) do not have any family history of medical or psychiatric illness. Regarding the developmental milestones, almost all the children have a delay in achieving it on time. After the IQ assessment, almost half of the children (45%) were diagnosed with mild mental retardation, 40% with moderate and 15% with severe mental retardation; along with this majority (60%) found to be having physical or psychiatric comorbid conditions. As per ADPMR scores, almost half of the children ($n=9$) has a moderate level of disability followed by mild and severe disability ($n=6$ & $n=5$ respectively).

The average IQ level of the children assessed by the psychologist is 47.85 ± 13.35 and mean percentage of disability was found to be 55.25 ± 15.76 .

Table 1: Correlation between the general health of the caregivers with the IQ and disability level of the children with intellectual disability

	Variables	Level of IQ	Level of disability (ADPMR)
GHQ - 28	Somatic Symptoms	-.263	.210
	Anxiety	-.052	.023
	Social Dysfunction	-.479*	.433
	Severe Depression	-.284	.243
	Total Score	-.321	.268

(* $p < 0.05$)

Table 1 shows the correlation between the general health of the caregivers with the IQ and disability level of the children with intellectual disability. The result showed that; the domain social dysfunction of GHQ has a significant negative correlation with IQ level of the children with intellectual disability ($r = -.479$, $p = .033$).

Table 2: Correlation between the psychological wellbeing of the caregivers with IQ level and level of disability in the children with intellectual disability

	Variables	Level of IQ	Level of disability (ADPMR)
Ryff's Psychological wellbeing	Autonomy	.132	-.140
	Environmental mastery	.061	-.097
	Personal growth	.221	-.079
	Positive relations	.287	-.411
	Purpose in life	.113	-.429
	Self-acceptance	.536*	-.446*
	Total score	.299	-.338

(* $p < 0.05$)

Table 2 shows the correlation between the psychological wellbeing of the caregivers with IQ level and level of disability in the children with intellectual disability.

Result showed that

- The domain, self-acceptance of Psychological wellbeing is having a significant positive correlation with IQ level ($r = .536$, $p = .015$) and has a significant negative correlation with the level of disability in the children with intellectual disability ($r = -.446$, $p = .049$).

Table 3

	Variables	Level of IQ	Level of disability (ADPMR)
FISC-MR-I	Daily care stress	-.458*	.586**
	Emotional stress	-.316	.264
	Social stress	-.263	.168
	Financial stress	-.277	.297
	Total score	-.438	.460*

FISC-MR-II	General Awareness	-.511*	.244
	Attitudes & Expectations	-.395	.309
	Rearing practices	-.402	.186
	Social support	-.348	.212
	Global family adaptation	-.432	.376
	Total score	-.504*	.321

(* $p < 0.05$), (** $p < 0.01$)

Table 3 shows the correlation between stress and coping of the caregivers with IQ level and level of disability in the children with intellectual disability. Result showed that

- Total score of section I of FISC-MR is having a significant positive correlation with the level of disability in the children with intellectual disability ($r = .460$, $p = .042$).
- The domain, daily care stress is having highly significant positive correlation with level of disability ($r = .586$, $p = .007$) and has significant negative correlation with IQ level ($r = -.458$, $p = .042$).
- General awareness of Section II has a significant negative correlation with children's IQ level ($r = -.511$, $p = .021$).
- The total score of [FISC-MR Section II] has a significant negative correlation with IQ level of children with intellectual disability ($r = -.504$, $p = .023$).

Table 4

	Variables	Level of IQ	Level of disability (ADPMR)
Social problem solving	Avoidance style	-.314	.251
	Negative problem orientation	-.406	.346
	Rational problem solving	.259	-.328
	Impulsiveness/ carelessness style	-.550*	.404
	Positive problem orientation	.504*	-.463*
	Total score	-.398	.207

(* $p < 0.05$)

Table 4 shows the correlation between social problem-solving ability of the caregivers with IQ level and level of disability in the children with intellectual disability.

Result showed that

- Domain, Impulsiveness/ carelessness style of SPSP-R is having a significant negative correlation with the IQ level of the children with intellectual disability ($r = -.550, p = .012$).
- Positive problem orientation is having significant positive correlation with IQ level ($r = .540, p = .024$) and has significant negative correlation with level of disability in the children ($r = -.463, p = .040$).

Table 5

	Variables	Level of IQ	Level of disability (ADPMR)
Self-determination	Awareness of self	.100	-.301
	Perceived choice	.208	-.153
	Total	.253	-.376

Table 5 shows the correlation between self-determination of the caregivers with IQ level and level of disability in the children with intellectual disability. The result shows there is no significant correlation between the variables.

4. Discussion

4.1 Socio-demographic profile

In the present study, out of the total 20 children with intellectual disability 65% of the children were males. Similar to the result, almost all studies report that the prevalence of mental retardation is higher among males than females. A number of reasons are suggested for greater prevalence in male children, including more frequent identification among boys' due to abnormal behavioural patterns in school and low birth-weight on neurological development among males (Leonard & Wen 2002). Based on data from the 2011 meta-analysis of international studies, the female-to-male ratio of children and adolescents with intellectual disability varied between 0.4 and 1.0 (i.e., four to 10 females with intellectual disability for every 10 males with the condition (Maulik, et al 2013). This high proportion of males can be due to the fact that female children are less likely to be brought for evaluation of MR due to various social and cultural factors. According to Nagarkar et al (2014) intellectual disability seemed to be prevalent more in the 1st and the 2nd order of birth rather than the consecutive ones. As parents grow older, siblings may become carers (Heller & Arnold 2010). Both benefits and disadvantages to siblings of children with intellectual disabilities have been reported in the literatures (Blacher & Begum 2011). The majority of the clientele of this institute comes from the lower or lower-middle socio-economic status, from rural areas and they are Hindu by religious affiliation. According to the Census 2001, 75% of persons with disabilities live in rural areas. It may be said that intellectual disability is more common in families of low income status. In the study done by Sekar (2016); 85 % of the mothers were housewives with only a few being in business with their husband. In comparison with other

mothers, mothers of children with disability are less likely to be gainfully employed or involved in full-time work (Lewis, Kagan, & Heaton, 2000); these mothers have considerable difficulties associated with employment due to the care demands of their child with disability and inadequate childcare support (Brandon, 2007). According to intellectual disability (ID) studies, mothers of children with intellectual disability are more affected than fathers concerning their wellbeing and participation in paid work (Olsson & Hwang, 2008). Some mothers left outside employment when they had a child with intellectual disability or because caring for a child with intellectual disability was extremely difficult (Chou et.al 2010). (Sekar 2016) found that it was mostly mothers who spent time with the effected child. In the study of Vidya Bhushan Gupta (2012) majority of the primary caretakers interviewed were mothers (86%) followed by fathers (6%). In several studies, it has been indicated that mothers of disabled children give up other roles in society, attend less to social activities, and have less social life due to their increased responsibilities for childcare.

4.2 Clinical characteristics

Out of the 20 children with intellectual disability, seventy percent of the children were born out of normal vaginal delivery and 30% had caesarean section. Sebastian (2015) in his review quoted that premature infants and those with intrauterine growth retardation are at special risk for damage to the cortex or thalamus, which, in addition to affecting intelligence, causes various symptoms of cerebral palsy (CP) and seizure disorder, depending on the location of the pathological condition; noted that asphyxia alone does not cause mental retardation. Neurologic symptoms during the neonatal period have a strong association with prenatal developmental deviations and later neurologic integrity and intellectual level. For these reasons, infants with perinatal problems need a thorough examination for dysmorphic features and close follow-up because multiple disabilities might become evident later in life.

Shah et al (2014) also reported the similar result that, delayed birth cry was the most frequent (21%), followed by presence of seizures in the first two weeks after birth (16%) and poor maternal nutrition during pregnancy (13%) in his study done in a tertiary care centre. The inquiry about the childhood medical history or behavioral history revealed that epilepsy was the most common problem, followed by recurrent respiratory / gastrointestinal infections, feeding problems/failure to thrive, trauma/poisoning and high-grade fever (Shah et al., 2014). Result obtained in the study done by Nagarkar et al. (2014) with a family history of mental retardation present in 5 patients (8.4%) and absent in 55 patients (91.6%). The family history of mental illnesses other than mental illness was evident in 2 patients (3.3%). Mahdi Foroutan (2014) showed a statistically significant correlation between a positive family history of mental retardation and MR severity, which might be regarded as evidence for the presence of genetic factors of MR. Delay in speech development was the universal finding seen in 96.7% patients. 86.7% patients had a delay in achieving sensory milestones and 76.7% patients reported a delay in achieving a motor milestone in a study conducted by Nagarkar et al. (2014). According to the study conducted by Tang (2008), the most common reason for referral to clinical setting was language delay (39%) and global developmental delay (30%). Majority of patients were having Mild to Moderate disability, followed by Severe and few of them Profound in the study of Shah et al. (2014). Also in

his study, co-morbid treatable psychiatric disorders, autism, conduct disorder or ADHD was evident 10-20% of cases. Russell et al. (1999) in their study among the 57 intellectually disabled children, there were 39 (68.5%) mildly, 12 (21%) moderately, four (7%) severely and two (35%) profoundly disabled children. Co-morbidities were reported in 53.33% (32 out of 60) patients while 46.7% patients (28 out of 60) did not have any co-morbidities and co-morbidities thus seem to be very common accompaniment with mental retardation in more than half of the study population (Nagarkar et al., 2014).

4.3 General Health of the caregivers with the level of IQ and level of disability in the children with intellectual disability

The result shows that higher the IQ level in the children, lower is the social dysfunction in the caregivers. This finding can be because the children with a higher level of IQ will be more efficient in doing their daily activities and personal care as compared to the children with lower IQ. These children might be more independent in doing their activities so, the caregivers of the children with comparatively higher IQ will have fewer demands on them, and hence they will be having more time for leisure and recreation. They need to put extra inputs of care, have decreased leisure time, neglect of others, personal distress, marital problems, other interpersonal problems and effect on siblings that may, in turn, affect their social functioning.

There is lack of published literature examining the level of IQ about the general health of the caregivers of children with intellectual disabilities. A higher level of IQ in the child is associated with less caregiver strain related to interrupted routines and other negative consequences (Kirby, White, & Baranek, 2015). Neece, Green, & Baker, (2012) found that there is a bidirectional relationship between parenting stress and child behavior problems for mothers and fathers. In a study conducted by Majumdar et al., (2005) report that mothers, who are housewives without additional help, can feel restricted in pursuing their social and leisure activities, and experience more stress.

4.4 Psychological wellbeing of the caregivers with the level of IQ and level of disability in the children with intellectual disability

The result shows that higher the level of IQ in the children, higher the self-acceptance in the caregivers and as the level of disability of children increases, the self-acceptance of the parents decreases.

The possible reasons can be many; when the level of intelligence in the children is low, the caregivers have to accept it since they had no other alternative as it is an unavoidable situation. The caregivers of children with comparatively high IQ might have more hope and thus prepared themselves for anticipated confrontations in the real world. They might have realized their potential and the ways of maintaining their quality of life in the midst of these challenges they face. The increased level of disability may result in decreased self-acceptance when the parents were also disturbed by the complexity of caring responsibilities that demanded a lot of work and is available most of the time to meet the daily needs of the child. In another word, higher the social disturbances caused by the disabled child, lower will be the positive coping strategies used by the

caregiver and sparse interpersonal interactions may make it difficult to obtain practical support. Raina et al. (2005) found that the most important predictors of caregivers' well-being were child behavior, caregiving demands, and family function. A higher level of behavior problems was associated with lower levels of both psychological and physical health of the caregivers, whereas fewer child behavior problems were associated with higher self-perception and a greater ability to manage stress.

4.5 Family's stress and coping of the caregivers with the level of disability and IQ level in the children with intellectual disability.

Loeb (1979) has expressed that parents of intellectually disabled children face many special stresses (Blessie 2015). They have little opportunity to explore their own needs and difficulties. As seen in the study result the magnitude of reaction to stress is considerably high for individuals with poor social support from close friends and family members than for individuals with adequate social support. Marika, V (1999) quoted that the tendency towards social isolation often encountered in families with a child with a disability may affect the mother in the form of a real or threatening exclusion from the social environment and may be an important factor in anxiety and stress (Sajjad, 2010). The absence of others in whom one can confide and from whom one can expect help and concern can result in high-stress level in caregivers with intellectual disability children (Burton et al., 2009). Coping with parenting stressors may depend on the parents' attribution to the stress sources. There is considerable research explaining that parenting stress, especially stress related to the child's temperament (such as demandingness, adaptability, acceptability, mood, hyperactivity/distractibility), often appears to be higher in the families with disabled child (Dyson, 1997). Another study by McBride, Schoppe, & Rane, (2002) highlighted another significant way in which child characteristics, particularly temperament, may influence parents through increased or decreased parenting stress. In a model of parenting stress analogous to Belsky's (1984) model of the determinants of parenting, Mash and Johnston (1990) proposed that child characteristics such as temperament influence parent-child interactive stress.

4.6 Social problem-solving ability of the caregivers with the level of disability and IQ level in the children with intellectual disability

The results reveal that the caregivers tend to have high impulsive/ careless problem-solving strategies with the children with a low level of IQ and when the level of intelligence is high in the children, the caregivers tend to use positive problem-solving strategies.

The possible reasons can be that parents with children having comparatively low IQ lack skills for dealing with everyday challenges associated with the care situation. The parents of children with intellectual disability might be having disturbing thoughts about living with a mentally ill child. They expressed being stressed by the explicit behavior of the child that caused problems not only for the parent but also to people nearby such as neighbors. Behaviors of the children that were of particular concern to parents were aggressive, destructive, restless or hyperactive, making noise, and lack of proper eating skills which are exhibited more by children with low IQ. Thus, caregivers with children having comparatively low IQ and high level of disability will be experiencing more

problems in tackling these social problems. Since the caregivers of children with IQ were required to function multiple roles and found them taxing. This might have affected their efficiency in solving social problems like dealing the stigma of having a disabled child reflected by a sense of powerlessness, shame, hostility and poor social support system.

Caregivers with a greater negative orientation were at risk to develop psychological and health problems at a significantly higher rate over the year. These persons are more likely to use palliative, emotion-focused coping strategies and have ruminative, irrational thoughts in time of stress that does not remedy problematic situations (D'Zurilla & Chang, 1995). Heppner and Krauskopf (1987) believe persons who have a negative appraisal of their problem-solving abilities are likely to encounter several difficulties processing problem-related information. Caregivers with a higher negative orientation might experience an unfortunate yet circular situation. They may have difficulties managing their own emotions and creatively meeting caregiving demands. When these problems are unresolved over time, pessimistic beliefs about the self may be reinforced, exacerbating their distress levels (Nezu & D'Zurilla, 1989). This cycle could contribute to the development of more emotional and health problems as the caregiving role unfold.

4.7 Self-determination of the caregivers with the level of disability and IQ level in the children with intellectual disability

Even though there is no significant relationship; the domains of self-determination is having a positive correlation with the level of intelligence and has a negative correlation with the level of disability in the children with intellectual disability.

The possible reasons can be that the caregivers of the children with intellectual disability had an unrealistic attitude towards their disabled children and showed protection for their children. They hoped for a miraculous cure and relied on fate. The prevailing attitude, superstition, and ignorance tend to be optimistic that their children will behave like a normal child. They would continue to have a higher expectation and pressurize the child to behave normally and finally become frustrated when their children fail to meet their demands. This happens because of the lack of information about intellectual disability and their abilities to tackle their children.

Lifestyle satisfaction is related to self-determination and may be largely influenced by external factors, such as social life, leisure activities, employment opportunities, and community services (Duvdevany, 2002). A person's relative self-determination is found to be a strong predictor of quality of life; people who are highly self-determined experience a higher quality of life (Wehmeyer & Schwartz, 1996). Self-determination has been characterized as a set of learned behaviors and skills, derived mainly from educational and home environments, which enable an individual to make decisions and solve problems. The actions of self-determined people allow them to fulfill roles typically associated with adulthood (Palmer & Wehmeyer, 1998). However, communicative initiative leads to self-determination only when others in the environment understand and respond appropriately (Olney, 2001). Therefore, education plays a critical role in achieving self-determination.

5. Conclusion

The family with a child with an intellectual disability may experience consequences to the entire family system. Parents whose children with intellectual disability experience behavioral problems have additional challenges and demands placed on them. These children may need more individual attention and effective behavioral intervention plans. Parents that reported significant behavior problems in their children had more stress, less happiness, less social support, and fewer family-centered school services than parents whose children did not have significant behavior problems. Parental age, marital status, and education level can also impact perceived stress about raising a child with intellectual disability. Parents who are very old or very young may be at a higher risk of experiencing stress.

The child's age was significantly associated with the parents' stress, and parental stress lessened when the child was older. Parents experienced more psychiatric symptoms when the child had a high severity level of disability. Furthermore, the severity of the disability was significantly associated with the parents' psychological distress. Low socioeconomic levels were correlated with higher cognitive disturbance, depression, anxiety, and despair in parents. Within the family environment variable, the personal growth dimension was found to be a predictor of parental stress.

6. Limitations

The sample size was small hence result cannot be generalized. There was no control group, and sampling was done in a purposive manner which if it had been randomized would have led to greater generalizability.

7. Suggestions

Based on the results and experiences obtained from the study, a planned education is recommended for the caregivers of all mentally handicapped individuals. The necessary steps for this purpose are; the provision of appropriate institutions to offer psychoeducation, as well as the formation of comforting counselling groups where the parents of a handicapped individuals meet other parents and express their feelings, meeting the supportive requirements with the aid of educational materials, encouraging the professionals to play a role in improving and applying educational program held with caregivers of handicapped individuals. Educational, informative and psychological counseling to the caregivers of mentally handicapped individuals will help them in adapting to their environment, in the best way. Psychiatric social workers have great responsibilities for the services offered to the families of mentally handicapped children. Qualitative research would be appropriate to identify any additional factors that may interfere with parents' psychological well-being and general quality of life

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