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Self-Esteem and Alienation in Parents Having Children with Intellectual Disability

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ABSTRACT

Intellectual disability is a complex, multidimensional health problem posing adverse social and psychological impacts on the parents having children with intellectual disability. This study investigates the impact of intellectual disability on the families having children with intellectual disability in terms of their alienation (social isolation) from the rest of the society and impact on their self-esteem. This is a cross sectional study in which 4X2X2 factorial design with categories of degree of retardation at two levels, age groups at 4 levels, and gender at two levels were used. Parents having children with intellectual disability were approached personally and tools standardized on Indian population Self Esteem and Alienation Inventories were administered on them. Scores of the subjects who had children with intellectual disability on Self Esteem was very high signifying negative self-esteem. Also, Alienation scores of the subjects were found to be more than the average, thus implying that there was a high degree of alienation of the parents who had children with intellectual disability from the society. We concluded that the intellectual disability is a condition which causes alienation of the parents having children with intellectual disability from the rest of the society and adversely affects their self-esteem.

KEYWORDS: Alienation, Intellectual Disability, Parents, Self-Esteem.

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INTRODUCTION

World Health Organization (WHO) reports that the prevalence of people with intellectual disability (formerly known as mental retardation) has reached up to 3% of the total population of the world¹. In India, people with intellectual disability accounts for 2 - 3%^{2, 3, 4, 5} out of which majority of them (approximately 85%) are people with mild intellectual disability⁶.

Intellectual Disability

There are several definitions of intellectual disability. One of them which is widely accepted and has been given by the American Association on Intellectual and Developmental Disability which defines intellectual disability as “*a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18*”⁷.

Classification of Intellectual Disability

During the last century, many development have taken place to classify or categorize people with intellectual disability on the basis of certain characteristics such as causal factors i.e. etiology such as genetics, environmental, and unknown factors, timing of the causation (prenatal, perinatal and postnatal), the degree of intellectual retardation on the basis of IQ (boarder line, mild, moderate, severe, or profound) and functioning level (educable, trainable and custodial). Medical Scientists focused on defining the causal factors i.e. etiology (genetic, environmental and unknown), timing of the event (prenatal, perinatal and postnatal). While Behavioral Sciences emphasis on the current level of functioning and the age of the child with intellectual disability with view to classify them in pre-primary, primary, secondary, pre-vocational and vocational levels⁸.

In WHO International Classification of Diseases version 10 Guide for intellectual disability and the levels of intellectual disabilities are indicated by IQ Ranges; each range i.e. category is based on the IQ scores obtained after administrating the standardized psychological scales to measure the "General Intellectual Functioning" of the individual. These categories are Mild intellectual disability (50-69), Moderate intellectual disability (35-49), Severe intellectual disability (20- 35) and any person with IQ below 20 is regarded as Profound intellectual disability⁹.

Causes of Intellectual Disability

Intellectual disability has many causes. It may be due to genetic or environmental factors. Some of the examples of genetic disorders associated with intellectual disability are: Down's Syndrome, Klinefelter Syndrome, Tay-Sach disease, Galactosmia, Microcephaly, Congenital Hypothyroidism, etc. Antenatal factors associated with intellectual disability are like Rhesus Incommutability, Neural Tube Defect, Infections, Drugs and Irradiation etc. Perinatal factors linked to this condition are like birth injuries, hypoxia, and Cerebral Palsy. Postnatal factors associated with intellectual disability are head injuries, encephalitis, accidents, chemical and physical agents, etc. Also, others factors contribute in causation of intellectual disability like Maternal malnutrition, Protein Energy Malnutrition, iodine deficiency, consanguineous marriage and late pregnancy after the age of 40 years¹⁰.

Clinical Presentation

Usually, the prominent clinical presentations in children having intellectual disability are seen with delay in receptive and expressive language skills acquisition. There are usually delay in developmental milestones, such as social skills, motor skills, and cognitive skills are also observed⁸. There is a link between the presentation of significant delay in gross motor, cognition, fine motor, personal and social, speech and language, daily living activities of children and the intellectual disability¹¹.

Diagnosis

Intellectual disability can be diagnosed by obtaining a careful prenatal, natal and postnatal history, concepts formation, academic history, family history, present history, including the demographic history of the person. This is helpful for comprehensive understanding of this condition particularly from medical, behavioral, special educational and therapeutic perspectives in making diagnosis and further decision about the person. A complete physical examination of the person is also useful in the diagnosis, in case if there are any associated conditions such as sensory and physical impairments. Sometimes it is advised to request a chromosomal analysis specially Fragile X Testing to show if there is a chromosomal abnormalities. The diagnosis of intellectual disability is completed by applying Standardized Measurement of Intelligence and Adaptive Skills to diagnose and to classify intellectual disability in various categories such as borderline, mild, moderate, severe or profound intellectual disability.

Self-Esteem and Alienation

Self-esteem is a term used to describe an individual's perception of his or her own worth. Francis offered a definition of significant self-awareness which states: "*Self-esteem is positive or negative way an individual views himself or herself. It also entails the desire to be held in high esteem by others*"¹².

Alienation is "*a condition in social relationships reflected by a low degree of integration or common values and a high degree of distance or isolation between individuals, or between an individual and a group of people in a community or work environment*"¹³.

The Social and Psychological Impact of Intellectual Disability

Living with a child having disability has profound effects on the entire family, parents, siblings, and extended family members. On the positive side, this condition can attract the family members to look on their strengths and can broaden family horizons, enhance family cohesion and bonds, and build a network connection with the community or religious institutions. On the other side, there is increase in financial costs and time consuming, along with emotional and physical demands. The impacts of having children with intellectual disability most likely depend on the severity of the condition, the emotional, physical, the financial status of the family and the resources that are available to the impacted families as well¹⁴. For parents, having a child with intellectual disability may experience stress while they are thinking about the mental and physical health of their children, and some cases they may face difficulties to find accessible and appropriate child care, and these issues may affect their decisions about work, education and training. It might also impact families to plan to get more children, and increase the dependence on public support. It may be associated with guilt, blame, or reduced self-esteem¹⁴. According to one view, having a child with special needs causes a crisis in the family. A lot of clinical observations demonstrate that parents having children with intellectual disability usually exhibit ambivalence, guilt, disappointment, anger, frustration, sorrow and shame. The parents of children having intellectual disability are not satisfied with their marriages and they have low social support, less physical well-being in comparison to the parents having normal children¹⁵. And these parents are in higher risk of developing several social problems within their family along with experiencing many emotional difficulties⁶.

Loss of Self-Esteem

Parents having children with intellectual disability experience a psychological and emotional stress and lack of emotional support. They may consider the child with intellectual disability as a threat to their

self esteem and they view themselves as a source of disability in their children ¹⁶. They strive to deal with the financial costs; parents also are confronted with new and unexpected experiences. Parents having children with disabilities are at risk of developing stress and lower their levels of wellbeing than that of the parents having normal children ¹⁷. The personal or intra-psychic coping resources (self-esteem) are predicting depression significantly in both parents of children with developmental delays ¹⁸. A similar finding was reported by studying the mothers of deaf children ¹⁹. They found that self-esteem can predict stress in parents of children having intellectual disability. Lower self-esteem levels in the mothers of children having intellectual disabilities are reported ^{20,21}. Attitude of people towards families of children having intellectual disabilities frequently results in stigmatization and contributes to feelings of alienation or social isolation ²².

The aim of this study was to examine the self-esteem and alienation of the parents having children with intellectual disability in relation to age group and sex of the child with intellectual disability. Focus was to investigate the effects of gender and age on the self esteem and alienation because of limited of the literature availability on these issues. So, this study was carried out with a view to assess the social and psychological impact of having children with intellectual disability on their parents in Indian context.

MATERIALS AND METHODS

Study Design: This is a cross sectional study designed by using 4x2x2 factorial design. It was divided into age groups at 4 levels, categories of degree of retardation at two levels and gender at two levels as shown in table 1.

Table 1: Sample Size and Research Design with the Main Variables:

Variables	Sub Variables							
	0-6 years		6-12 years		12-18 years		18 and above	
Degree of retardation	Mild	Severe	Mild	Severe	Mild	Severe	Mild	Severe
Parents having male	12	12	12	12	12	12	12	12
Parents having female	12	12	12	12	12	12	12	12
Total Sample (192)	48		48		48		48	

The Participant: Parents having a child with Mild/Severe intellectual disability in the family were included in this study. A sample of 192 respondents was selected from the voluntary agencies (5 Non-Governmental Organizations functioning in Northern India). Simple random technique was used to

gather the data considering the objective of the study. The respondents (i.e. parents of children with mild/severe intellectual disability) were drawn from the list of persons with intellectual disability registered for daycare and home-based services in these non-governmental organizations included in this study. Parents having children with intellectual disability who had been diagnosed with either mild or severe degree of retardation were approached personally for the interviews.

Tools: A questionnaire that contained demographic variables and the Self Esteem Inventory which was developed by Prasad and Thakur²³ was used to gather the data. This inventory takes into account personally perceived self and socially perceived self. Therefore, there were three possibilities; (1) person having positive self in which the personally perceived score is higher than the socially perceived score (2) person having negative self in which personally perceived score is lower than the socially perceived score; and (3) balanced self-esteem there is no difference between the two. And this test showed a high validity and reliability; Split half reliability co-efficient were calculated for both the sets of the inventory which came out to be 0.82 and 0.78 for personally perceived self and socially perceived self respectively. Retest reliability co efficient were found for both the tests were 0.9 and 0.66 respectively for personally perceived self and socially perceived self.

The Alienation scale developed by Patil²⁴ was used to gather data in order to measure the degree of alienation of parents having children with intellectual disability from the society. The split half reliability (correlating the odd-even items) of the test Spearman -Brown formula for doubling the length was found to be 0.88, with an index of reliability of 0.943. The test retest reliability was found to be 0.82, with an index of Reliability of 0.897. All the values are highly significant at 0.01 level of confidence. Regarding the validity of the scale, only diagnostic items are included in the scale following item analysis. The upper and lower 25% served as criteria groups'. The coefficient of correlation of the Scale with Reddy Mall's Alienation scale and Kureshi and Dutta's. The Alienation scale are found to be 0.76 and 0.73 (N=100) respectively.

Ethical Approval

The authors declare that this manuscript does not contain clinical studies or patient data.

Informed Consent

Informed consent was obtained from all individual participants included in the study.

RESULTS AND DISCUSSION

This study reports the impact of having a child with intellectual disability on self-esteem and alienation of the parents.

Table 2: Mean and SD Scores on Self-Esteem & Alienation:

Variables	PP	SP	TS	AL
Mean	129.35	134.17	263.52	44.47
SD	13.03	6.63	15.11	7.15

PP = Personally Perceived Self Esteem, SP = Socially Perceived Self Esteem, TS = Total Self Esteem, AL = Alienation.

The personally perceived self-esteem and socially perceived self-esteem of the subjects having children with intellectual disability was found to be very high signifying negative self-esteem. Also, the alienation score was found more than the average, indicating that the subjects are highly alienated from the rest of the society. Similar findings have been reported^{25, 26}. Subjects tend to develop negative self due to multiple reasons: the societal attitudes towards persons with intellectual disability add to their agonies, the presence of a child with intellectual disability is treated as an additional burden on the family, the parental expectations are not fulfilled by their children with intellectual disability they tend to develop psychosomatic disorders. All these factors contribute in subjects and they develop negative self which ultimately leads to their alienation from the rest of the society.

Table 3: Inter Correlations Matrix of Entire Sample on All Variables:

Variables	PP	SP	TS	AL
PP	1.00	0.09	0.90	-0.00
SP		1.00	0.51	-0.08
TS			1.00	-0.04
AL				1.00

The personally perceived self-esteem was found to be positively correlated with socially perceived self-esteem and total self-esteem. Socially perceived self-esteem was found to be positively correlated with total self-esteem and negatively correlated with alienation. Total self-esteem was also found to be negatively correlated with alienation. It indicates the parents having low self-esteem will be alienated more from the society.

Table 4: Analysis of Variance Alienation (Category X Gender X Age):

	Df	SS	MSS	F Value
Category	1	1900.083	1900.083	64.03549
Gender	1	130.021	130.021	438189
Age	3	1855.625	618.542	20.84573
Category X Gender	1	3.521	3.521	.011866
Category X Age	3	149.042	49.681	1.67430
Gender X Age	3	33.854	11.285	0.38031
Category X Gender X Age	3	481.437	160.479	5.40837
Residuals	176			

The two categories (Mild and Severe) intellectual disability differs significantly from each other on alienation. Observation of mean values depicts that the subjects having children with severe intellectual disability obtained higher mean value than those subjects having children with mild one. Also, the subjects having male and female children with intellectual disability differed significantly on alienation with preference to the female side. All the four groups of different age groups of intellectual disability obtained very high and significant F ratio on alienation and it indicates that subjects having children with intellectual disability of all the age groups differ from each other on alienation. The F ratio for gender X age is found to be statistically insignificant, so, the gender is independent of ages. It implies that the sex levels when interact with different age groups do not differ significantly on alienation. The F ratio for three factor interaction effect category X gender X age emerged to be statistically significant, indicating that all the three main effects when interacting with each other exerts significant effect on alienation. Similar findings have been reported ²⁵. So, it can be inferred that alienation is affected by the collective interactive effect of all the main effects.

Table 5: Analysis of Variance Personally Perceived Self (Category X Gender X age):

	Df	SS	MSS	F Value
Category	1	75.00	75.00	0.505964
Gender	1	918.75	918.75	6198054
Age	3	2211.17	737.0556	4.972310
Category X Gender	1	18.75	18.75	0.126491
Category X Age	3	1592.25	530.75	3.0580536
Gender X Age	3	1135.0	378.3333	20552305
Category X Gender X Age	3	414.17	138.0556	0.931348
Residuals	176	26088.83	148.2320	

The F ratio is found to be statistically insignificant on personally perceived self-esteem. It implies that the subjects having mild and severe children with intellectual disability do not differ from each other on personally perceived self-esteem. The F ratio for gender is found to be statistically significant on personally perceived self-esteem. It implies that the subjects having male and female children with intellectual disability are differing from each other on personally perceived self-esteem. Also, it implies that the subjects having children with intellectual disability of different age group are differing from each other on personally perceived self-esteem. It is found that the personally perceived self-esteem of the subjects having children intellectual disability of 12-18 years was the highest followed by 0-6, 6-12 and 18 years and above. Hence, the mean difference was observed to be the real difference on this variable. The F ratio for two interaction effect category x gender is statistically found insignificant. It leads us to conclude that the effect of subjects having mild and severe children with intellectual disability is independent of gender on personally perceived self-esteem. The F ratio for gender x age is statistically found to be insignificant on personally perceived self-esteem. It implies that the effect of subjects having male and female children with intellectual disability is independent of different age groups on personally perceived self-esteem. The F ratio for the three factor interaction effect for category x gender x age is found to be insignificant. It can be said that all the three main effects of the study when interacting with others do not affect significantly on the personally perceived self-esteem of the subjects having children with intellectual disability.

Table 6: Analysis of Variance Socially Perceived Self-Esteem (Category X Gender X Age):

	Df	SS	MSS	F Value
Category	1	114.08	114.08	2.51
Gender	1	21.33	21.33	0.47
Age	3	82.45	27.48	0.60
Category X Gender	1	18.75	18.75	0.41
Category X Age	3	46.87	15.62	0.34
Gender X Age	3	28.04	9.34	0.20
Category X Gender X Age	3	105.12	35.04	0.77
Residuals	176	7970.0	45.28	

The F ratio for the categories seems to be statistically insignificant. It implies that the subjects having mild and severe children with intellectual disability effect on gender are independent of the categories of intellectual disability. Furthermore insignificant F ratio was obtained from category x age

and it implies that the effects of subjects having mild and severe intellectual disability are independent of different age groups of children. Similarly F ratio for "gender X age" is also found to be statistically insignificant. It implies, the difference between subjects having male and female children is approximately same regardless of their age groups on socially perceived self-esteem.

The F ratio for the three factor interaction effect (category x gender x age) is also found to be statistically insignificant for socially perceived self-esteem. It can be said that all the three main effects of the study when interacting with others do not affect significantly on the socially perceived self-esteem of the subjects.

Table 7: Analysis of Variance Total Self (Category X Gender X Age):

	Df	SS	MSS	F Value
Category	1	4.08	0.01	0.019
Gender	1	12220.08	5.87	5.87
Age	3	2576.62	4.13	4.13
Category X Gender	1	75.00	75.00	0.36
Category X Age	3	1769.96	589.68	2.83
Gender X Age	3	1148.04	382.68	1.84
Category X Gender X Age	3	222.29	74.09	0.35
Residuals	176	36571.83	207.79	

The data imply that the subjects having mild and severe children with the intellectual disability do not differ from each other on total self-esteem. The F ratio for gender is found to be statistically significant on total self-esteem and it implies that the subjects having male and female children with intellectual disability do differ from each other on total self-esteem. The F ratio for two factor interaction effect "Category x Gender" on total self is found to be statistically insignificant. It implies that the difference between subjects having mild and severe children with intellectual disability is approximately same regardless of different age groups. The insignificant F ratio was also obtained for Gender x Age on total self-esteem. It implies that the effect of subjects having male and female children with intellectual disability is independent of age groups. The F ratio for the three factor interaction effect "Category x Gender x age" on total self-esteem is found to be statistically insignificant on total self-esteem. It implies that all the three main effects of the study when interacting with others do not affect significantly on the total self-esteem of the subjects.

CONCLUSION

The present study concludes that the self-esteem of the parents having children with intellectual disability is negative and the alienation of the parents having children with intellectual disability was found to be highly alienated from the rest of the society.

Study further finds that the parents having children with mild intellectual disability are comparatively less alienated from the society, than the parents having children with severe intellectual disability. Similarly, the parents having female children with intellectual disability were found to be more alienated than the parents having male children with intellectual disability. And this implying the Intellectual disability exerts its negative social impacts on these families.

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Conflict of Interest

The authors declare that there are no conflicts of interest.

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