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DISABILITY IMPACT AND QUALITY OF LIFE IN PARENTS OF CHILDREN WITH INTELLECTUAL DISABILITY

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ABSTRACT

Background: Presence of an intellectual disabled child in a family creates continuous stress among the family members. They undergo with lots of emotional problem and very much worry about the safety and development of their children. The whole family gets affected to this disabling condition and show impairment in their functioning and quality of life. Aim: This study attempted to measure the disability impact and quality of life of parents having intellectually disabled children and compare the disability impact and quality of life between fathers and mothers of intellectually disabled children. Design: This study was a cross sectional hospital based study conducted at outpatient department of the institute. Sample: The study sample consisted of parents of 105 intellectually disabled children of different IQ level (30-Mild, 30- Moderate and 30 Severe) and their parents. Convenience sample was drawn and Disability Impact Scale, WHO-QOL Brief scale were administered on parents. Results: There are significant differences in disability impact scores in all domains except career among the fathers and mothers. There are significant differences in quality of Life in all domains among fathers and mothers. Conclusion: Contrary to the previous literature this study have shown many positive effects of having an intellectual disabled children. This is because of continuous exposure of parents in different parental education and training programme emphasizing the application of effective coping mechanisms.

KEYWORDS: Disability, Quality of life, Intellectual disability, Families of children with Disability

INTRODUCTION

Every parent dreams to have a healthy child and the birth of a child is one of the most happiest moments in their lives. They start to think about the future of their children with lots of hope and expectation and work hard to fulfil the needs of their children. But giving birth of a child with disability shatter the hope of parents and they undergo with lots of emotional problem and very much worry about the safety and development of their children. Specifically the presence of an intellectually disabled child has several social and emotional impact on parents as well as other members living with the child as they have to provide long term support and security to the child.

In India about 2% of the population is affected with intellectual disability or mental retardation 48 , and its prevalence varies from 0.22-32.7 per thousand populations 48,5 . Mental retardation is defined as a condition "significantly sub average general intellectual functioning, resulting or associated with concurrent impairment in adaptive behaviour and is manifested during the developmental period"(AAMD) 46 .

Mental retardation makes a person incapable of living an independent life. These children have special needs that demands more care and attention than the care of normal children. As this condition is chronic and non curable, parents frequently exhibit substantial amount of stress relating to child's characteristics such as severity of retardation, behavioural problems, associated medical conditions etc. Conditions like lack of financial and social support, prevalence of stigma and negative attitude of people also produce stress among parents

Literatures also indicate many emotional and psychosocial problems such as parental tension ¹², frequent conflicts and disputes in the family ³² reduce opportunity for social interaction, feeling of rejection, social isolation ^{17,26,2}, marital disharmony _{37,40} due to presence of an intellectual challenged child in the family. Health related problems such as poor health of mother¹⁵, reduced self esteem, depression, anxiety

are also noticed in the parents $^{\circ}$. Studies have also revealed that the presence of an intellectually disabled child affects the normal development of other siblings $^{2.16}$.

In a study the author compared parental stress in parents of disabled children and reported mothers felt more stress in parent domain than fathers, but both parents experienced high level of stress in child domain 3 . Other studies also reported that the parents of mentally retarded children had low level of sound mental health because of high level of perceived stress. 36,38,42 . In a study it is mentioned that mothers of mentally retarded children experienced high level of anxiety and stress as compared to the mothers of normal children. 21

While measuring the perceived stress of mentally challenged individuals authors also have reported that most of the parents felt mild to moderate stress but mothers have shown higher stress compared to fathers 45 .

The process of deinstitutionalisation and home based care has resulted many adverse consequences such as increased burden and impaired quality of life of family members. Simultaneously deinstitutionalisation also emphasizes on the assessment of quality of life in order to develop various psychosocial models to enhance the wellbeing and quality of life of child and family members having intellectually disabled children. According to the World Health Organization, quality of life concerns the subjective perception of the individual 19 about his place in life according to the cultural context and value system in which he lives and develops, depending on his personal its goals, expectations, interests, standards and concerns ⁴⁷. In India, family bears all responsibility of caring for such children and particularly parents are more affected by the condition and burden is experienced in several sphere of family functioning that affects the parents' personal and psychological well-being. Some studies reported that presence of an intellectually disabled child affects the quality of life of their parents 11,34

Parents who have children with disabilities often report that they have physical and psychological problems related to the care of their children, which has a direct impact on them and affects their quality of life 22 . Impairment in quality of life also attributed to factors such as the child's personality, the severity of disability , the family style 25 , the severity of the child's disability 18,44 , stress, environmental and social impact and level of support .

AIM:

This study attempted to measure the disability impact and quality of life of parents having intellectually disabled children and compare the disability impact and quality of life between fathers and mothers.

MATERIAL AND METHODS

Venue: This study was conducted at Institute of Mental health and hospital, Agra.

Design: This study was a cross sectional hospital based study conducted at outpatient department of the institute.

Sample: The study sample consisted of parents of 105 intellectually disabled children of different IQ (30-Mild, 30-Moderate and 30 Severe) and their parents. Convenience sample was drawn using the following inclusion and exclusion criteria.

Inclusion And Exclusion Criteria:

- 1. The age range of the children were 5 to 15 years.
- ICD-10 criteria was used to diagnose the children with the IQ less than 70 as assessed by the trained clinical psychologist using standardized psychological tests such as
- [Vineland Social Maturity Scale (VSMS) and Developmental Screening Test (DST)]
- Children having any major physical illness were excluded.
- 5. The age range of parents were 20 to 55.
- 6. Parents who gave their consent to participate in the study
- Parents with any psychiatric condition and major physical disorder were excluded.

Ethical Considerations: Written informed consent was taken from each parent of intellectually disabled children for participation in the study after explaining the purpose of the study and assurance is given to maintain the confidentiality. All the parents are allowed to withdraw themselves at any stage of the study in case of inconvenience.

After getting the consent from each parent the investigator applied the following tools for measuring the study variables.

Study tools: A self-designed semi-structured questionnaire was used to record the sociodemographic and clinical details of each child and their parents.

Disability Impact Scale: This was developed by National Institute for the Mentally Handicapped, Secunderabad and was used to assess the impact of disability on caregivers of the mentally challenged children. This is a culture specific tool which could be used to identify and assess the following:(a) The nature and degree of impact on the parents (both positive and negative) because of having a child with mental retardation. (b) The nature and degree of impact on the family members and the relationship within the family. (c) The nature and degree of impact with regard to relationships outside the family. (d) To identify trust area for family intervention programs. (e) To objectively evaluate family intervention programs. The 11 areas of impact included in the scale are as (1) Physical care, (2) Health,(3) Career (4) Support (5) Financial (6) Social (7) Embarrassment/Ridicule (8)

Relationships (9) Sibling effects (10) Specific thoughts (11)

WHO-QOL Brief: This scale is developed by the WHO. This consists of 26 items that measures QOL in four domains (1) Physical, (2) Psychological, (3) Environmental, and (4) Social relations). Higher the score in each domain better will be the QOL.

Statistical Analysis: The data is processed through SPSS 16.0 and following results were obtained.

RESULTS:

Table: 1 Sociodemographic and clinical characteristics of children.

Variables		Mean & SD	Percentage
T (C1:11/T		/Number	
Age of Child (In ye		10.35 ± 10.35	
Age of child at tim			
Sex:	Male	62	59.04%
	Female	43	40.96%
IQ level:	Mild	35	33.33%
	Moderate	35	33.33%
	Severe	35	33.33%
Behavioral	Present	30	28.57%
problems	Absent	75	71.43%
Education:	Pre-primary	38	36.19%
	Primary	21	20.00%
	Secondary	25	23.80%
	Prevocational	21	20.00%
Birth order :	First	49	46.70%
	Second	41	39.00%
	Third	15	14.30%
Family history of	Present	15	14.30%
ID:	Absent	90	85.75%
Family history of	Present	18	17.14%
mental illness	Absent	82	82.86%
Nature of	Normal	50	47.61%
delivery:	Caesarean	48	45.71%
	Forceps	07	06.68%
Place of Delivery:	Home	39	37.14%
_	Hospital	61	62.86%
Complications	•		44.76%
during: birth			55.24%
Postnatal	Present	16	15.23%
complication:	Absent	89	84.77%

Table -1 describes the sociodemographic and clinical characteristics of children of intellectually disabled children. The mean and SD of age of the children was 10.35 ± 10.35 years . Equal number of children (33.3%) were participated in each category (mild, moderate and severe) as per the study design. The ratio of male and female intellectually disabled children was 59.04% and 40.96%. Majority of children did not have any family history of intellectual disabled (85.75%) and mental illness (82.86%). Highest number of children were the first child of their parents. All the children were attending the special school and maximum children were in pre-primary class. (46.7%). Few children were born through forecep delivery (6.68%). Birth complication was noticed in 44.76% children during birth and complication after birth was seen in 15.23% children.

Table: 2 Sociodemographic and clinical characteristics of parents.

Variables		Mean & SD	Percentage
		/Number	
Father's age at bir	th of child	25.61± 4.71	
Mother's age at bi	rth of child	28.61± 4.37	
Fathers'	Unemployed	9	8.6%
Occupation	Business	56	53.3%

	Service	40	38.1%
Mothers'	House wife	72	68.6%
	nouse wife	-	
Occupation	Business	14	13.3%
	Service	19	18.1%
Socio-economic	Low	30	28.6%
Status	Middle	53	50.5%
	High	22	21.0%
Complication	Yes	47	44.8%
during Pregnancy	No	58	55.2%
Attempt to	Yes	17	16.19%
abortion	No	88	83.81%

Table: 2 shows the sociodemographic and clinical characteristics of parents. The age of fathers at the time of child's birth was 25.61 ± 4.71 and mothers was 28.61 ± 4.37 . Majority of fathers were employed and only 8.6% were not employed. 68.6% of mothers were housewives and engaged in household activities. Only 31.4% mothers were employed either in service or small business. 50.5% parents belonged to middle socioeconomic status. Complication during pregnancy was noticed in 44.8% parents.

Table 3: Impact of intellectual disabled on the Parents

Areas	Maximum	Obtained	Percentage
	scores	scores	
Physical care	4620	1709	36.99%
Health	3360	723	21.51%
Career	2940	412	14.1%
Support	3780	1009	26.69%
Financial	3360	1404	41.78%
Social	2520	858	23.21%
Embarrassment/Ridicule	2940	675	22.95%
Relationships	3780	987	26.11%
Sibling affect	4200	920	21.90%
Specific thoughts	2940	651	22.11%
Total negative impact	34440	9348	27.14%
Positive impact	3780	2049	54.20%

Table -3 shows that the positive impact on parents are more than the negative impact due to the presence of an intellectually disabled child. More negative impact is noticed in financial, Physical care, support and social domain.

Table:4 Comparison of Disability impact in male and female parents

temale parents	iemaie parents						
Dimensions	Groupi	N	Mean	Std.	t-	Significa	
	ng			Deviation	value	nce level	
Physical care	Fathers	105	08.64	2.18	8.48	.01	
	Mothers	105	12.85	2.35			
Health	Fathers	105	11.46	2.77	3.84	.01	
	Mothers	105	13.45	4.53			
Career	Fathers	105	09.77	2.4	.08	NS	
	Mothers	105	09.74	2.51			
Support	Fathers	105	12.85	2.35	7.46	.01	
	Mothers	105	15.73	3.19			
Ridicule	Fathers	105	08.43	1.97	3.94	.01	
	Mothers	105	09.41	1.62			
Finance	Fathers	105	11.7	1.51	9.02	.01	
	Mothers	105	09.59	1.85			
Relation	Fathers	105	09.56	1.93	7.04	.01	
	Mothers	105	11.5	2.06			
Social	Fathers	105	10.29	2.62	6.29	.01	
	Mothers	105	08.42	1.55			
Impact on	Fathers	105	08.43	1.9	3.48	.01	
siblings	Mothers	105	07.54	1.78			
Total negative	Fathers	105	09.53	1.75	7.88	.01	
impact	Mothers	105	11.5	1.86			
Specific	Fathers	105	13.45	4.53	3.84	.01	
thought	Mothers	105	11.46	2.77			

Table-4 shows the comparison of disability impact on both

fathers and mothers of intellectually disabled children. There are significant differences in disability impact scores in all domains except career among the fathers and mothers. Mothers are more affected in domains such as physical health, support, relations, ridicule domain where as fathers are more affected in finance, specific thought , impact on sibling and social domain. No impact is observed in career domain in both the groups.

Table:5 Comparison of Quality of Life $\,$ in male and female parents

Dimensions	Groupi	N	Mean	Std.	t-	Significa
	ng			Deviation	value	nce level
QOL: Physical	Mothers	105	15.73	3.19	7.46	.01
Health	Fathers	105	12.85	2.35		
QOL:	Mothers	105	11.46	2.77	3.84	.01
Psychological	Fathers	105	13.45	4.53		
QOL: Social	Mothers	105	08.64	2.18	8.48	.01
Relation	Fathers	105	11.62	2.87		
QOL:	Mothers	105	23.8	4.12	7.653	.01
Environment	Fathers	105	16.97	8.16		

Table-5 shows the comparison of Quality of life among fathers and mothers of intellectually disabled children. There are significant differences in quality of Life in all domains. Mothers quality of Life are more affected in domains such as Physical Health and Environment domain where as fathers quality of Life are more affected in domains such as psychological and social relation domains.

DISCUSSION:

This study aimed to describe the impact of having an intellectually disabled child in a family and how it affects the quality of life of parents. The results revealed that 36.99% parents had experienced burden in physical care and 21.51% had developed some health issues. Prior studies also reported similar results where it is mentioned that majority of family members (60%) felt severe burden with regard to their health. In care-giving process some parents needs to take care of their severely intellectually disabled children who are immobile and completely dependent on them for their daily activities. This custodial care makes the parents more tired and burdensome and they might develop health problems.

In the present study, 86% of parents didn't have any impact on their career adjustments to support an intellectually disabled child which is similar to the findings of other studies 45. This might be due to the fact that in India most of the mothers are house wives and are not career oriented. Fathers always tries to focus on the education of their children, prefers to remain in one place having better education facilities for their children and even some times forgo their promotion. 26.69% parents felt that they are not getting support from their neighbours and relatives. In a study it is stated that relatives ignores the family with intellectual disabled child for which that family many times live in isolation. 33 24 The highest number of parents (59.58%) faced financial crisis due to an extra demand for fulfilling the special needs of disabled child. Providing a support teacher, special services such as physiotherapy, occupational therapy and speech therapy as per the need of the child is very expensive that obviously puts the parents in financial crisis. Negative impact on the parents' of the intellectually disabled children in the form of financial crisis was also noted by Datta. 10 Financial burden is also reported by other studies. 13 35 The present study revealed that 23.21% parents felt embarrassment and 22.95% parents tried to keep themselves in social restriction. Due to prevalence of stigma in the society people often tries to keep their children away from the disabled child and avoids the family having a disabled child. The current transition period of urbanization and moving towards a single family system might doubles the social restriction in parents.

26.11% parents are thinking negatively that they could not maintain proper relationship with the relatives and 21.90% are worried about the future of their other children as they are not able to give proper attention to them due to the presence of an intellectually disabled child. Child's behavioural problems often create hindrances in daily routine activities of the family members and expressed emotion of family members and neighbours might lead to unhealthy relations. Similar to our findings in a study it is reported that higher percentage of parents felt that they were giving less time to their siblings 14.41. 22.11% parents have specific common thoughts such as separating the child away from the family and what will happen to the child after their (Parent) death . Majumdar found that the parents of mentally challenged children were more vulnerable to stress than parents of normal children, which is more or less similar with the present study 23,35

In the present study it was found that parents' felt maximum positive impact (54.20%) as compared to total negative impact (27.14%) of having an intellectually disabled child in a family. This positive impact may be due to acceptance of children in the family, better coping mechanisms of parents, involvement with similar parent group and sharing their views, seeking help from various govt. and private organisations, development of social networks etc. Searching ways of enjoyment and developing strong feeling of spirituality also creates a feeling of increased self esteem positivity. Authors have also reported that parents with intellectually disabled children used 'spousal support', 'participation in similar kind of parents groups', and 'religious beliefs' to cope with the challenges of rearing a disabled child. In a study Kazak and Marvin 20 pointed that despite the presence of high levels of stress, the families were found to have successful coping strategies. Canam 6 also pointed out that effective coping strategies helps the parents to overcome the day-to-day stressful situations and increase the family adaptability. Ramey and Keltner 30 in their study reported that both the informal and formal support systems have significant and pervasive effects on parental well-being. Similarly, culture and ethnicity exert influences on families through belief systems and culturally endorsed practices. However, the quality and quantity of the impact experienced may be quite individualized for each parent depending upon the nature of support available to them such as emotional, physical or financial support.

Other factors such as coping skills of parents themselves, child characteristics such as age, level of mental retardation, presence and absence of associated conditions etc. may also contribute immensely how far parents are able to face the challenge of having a child with intellectually disabled. 29 .

Many studies have revealed that parents of children with disabilities had impaired quality of life compared to parents of children without disabilities. 31,4,7 Kumar et al. while studying the quality of life of parents of Intellectually disabled children and children with CP found that parents of both the groups scored low in comparison to normal indicating impaired quality of life. A study pointed that fathers of children with disabilities had a better quality of life compared to the mothers of children with disabilities.8 But the current study have shown that mother's quality of Life are more affected in domains such as Physical Health and Environment domain where as fathers quality of Life are more affected in domains such as psychological and social relation domains. Study on children with PDDs also reported that mothers of children with PDDs showed impairment in the domain of physical health, social relationship and in the psychological state of quality of life while fathers showed impairment in psychological state and impairment in overall QOL and in social relationship.

Most of the mothers spend a large portion of their time in taking care of their children and pay very little time for their

own care and health. Sometimes they even ignore their health problems and due to this negligence more impairment in health related quality of life is observed. In Indian set up mothers usually take the whole responsibilities of rearing the child often confronts certain environmental issues such as being teased or rejected, financial problems, living arrangements, unmet needs, the problems associated with school and related services and worries about the future of their children which puts lots of stress and burden might lead to impairment environment related quality of life. 31,4,8 Similarly fathers are the earning source of the family, engaged in different occupation could not find time for social participation. Failure of their children in achieving the normal routine tasks creates a feeling of insecurity and fear of isolation from the community participation often disturbs their mind with ample number of unnecessary irrelevant

CONCLUSION:

Presence of an intellectual disabled child in a family creates continuous stress among the family members. The whole family family gets affected to this disabling condition and showed impairment in their potentials and quality of life. Contrary to the previous literature this study have shown many positive effects of having an intellectual disabled children. This is because of continuous exposure of parents in different parental education and training programme emphasizing the application of effective coping mechanisms.

Limitations:

- Sample did not mention the associated conditions with ID
- It compares only the gender but not other socio demographic variables.
- It has not used any additional information sheet for parent's feedback and suggestion to improve their quality of life.

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