Original Article

Quality of Life and Family Burden between Parents of Children with Intellectual Disability, Mathura,Uttar Pradesh.(UP)

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Abstract

Background: A child born into family is usually received with joy and considered a blessing but when the child is intellectual disability then blessing is clearly mixed. Acceptance of child with intellectual disability becomes difficult to parents along with family particularly when competence and achievement are very much valued in modern world. A parent shows a series of reactions shock, denial, guilt, sorrow, rejection and acceptance after knowing that their child is intellectual disabled. This study is based on quality of life and family burden among parents of children with intellectual disability and it is gender-based study. **Aim:** To study the gender differences in term of Quality of Life and Family Burden among parents of children with intellectual disability. **Methods and Material:** It is cross sectional study conducted at Mathura, Uttar Pradesh. Samples were recruited through purposive sampling technique. Semi-structured interview schedule was developing to assess the demographics profile, Quality of life scales and family burden schedule were administered on parents of children with ID. **Results and Conclusion:** Finding of this study showed that mother of children with intellectual disability have poor Quality of Life and high level of burden in comparison to the father of children with intellectual disability.

Keywords: Temperament, parental bonding, adverse childhood consequences.

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Introduction

Parenting of children with intellectual disability is more challenging in comparison to normal children. They are facing more complexity in their life and challenges in rearing of child. Finding of many research study suggested that parent know about the children's disabilities then they have reported acute shock, disbelief and pain. Intellectual Disability (ID) as it persists throughout lifetime. It contributes to 1.2% of the mental illness in Kerala (Celine & Antoney;2014). ID is the most prevalent childhood psychiatric disorder, among them, majority of the cases (85%) belong to mild mental retardation(Harris, J. C; 2006, Ganguli, H.C; 2000)A Meta-analysis on the prevalence of intellectually disabled children shows that 10.37/1000 population are affected Maulik et. al; 2011).

Parents with children having intellectual disability use various coping strategies, which are ineffective most of the time. Parents with children having intellectual disability experience more stress compared to their counterparts, who have children with no intellectual disability(Gupta & Kaur;2010). Quality of Life is a complex concept so difficult to explain in one definition, as there is no consensual definition of it and it can mean different things to different people (Memisevic et.al ; 2017).The concept, family burden, was noticed first by Grad and Sainsbury. They mentioned it as the negative expenditures created by the intellectually disabled children for their families(Chou K.R; 2000). Intellectually disabled children significantly affect how their families live (Sari & Basbakkal; 2008, Houtrow & Okumura; 2011).

Disability of children creates many changes in life of parents and become cause of many burdens in family, role and responsibilities of family members start to change. These changes reflect in private living space, social environment, expectations, family plans and careers. Many other factors like economic status, education, profession, marital adjustment and cultures of parents, poor social support, difficulties in communication, severity of disability, children's age are highly associated with parenting stress (Pelchat et.al; 1999).Chronic stress causes families to have more perceived problems and raises their anxiety levels. It also causes serious problems with coping and worsens the family burden. Studies indicate that families face the most stress during the diagnoses, and families' energy levels are diminished as children's dependency on their parents increases. Family members start to lock themselves in the house, and their private lives are disturbed. Social isolation and loneliness can occur. This diminishes satisfaction with life and quality of life (Deniz, Dimac & Aricak; 2009). This disease affects not only nuclear families, but also extended families Gopalan & Brannon; 2006). Parents of children with intellectual disability have facing more difficulty in their marital life due to stress of child's disability because they unable to spare quality of time with each other and sometime blaming for this each other (Sari, Baser & Turan; 2006). A study of the couple having children with ID highlighted that couples do not display the same level of coping feel that they are not supported by their partners and feel emotions such as anger, vexation and despair. In particular, mothers undertake the main responsibility to provide care and thus get angry more frequently. This anger also affects families. The siblings of children with deficiencies are deprived of the attention of their parents when these children become the focus of attention. This causes tensions between the subsystems covering parents and sibling semphasized that quality of life negatively related with economic family burden, family functioning, family relations, interpersonal relations of parents, other family burden(Kumar,P et al;2019) .

Kumar, P et al (2019) found that quality of life negatively related with economic family burden, family functioning, family relations, and interpersonal relations of parents, other family burden and the quality of life positively related with intellectual functioning. It indicates that the level of intellectual functioning increased than quality of life become well.

Gallagher et al.,(2008) suggested that parents of children with intellectual disabilities have report higher levels of depression and anxiety. Ravindranadan, V., & Raju, S. (2008) also found that there is no gender difference in emotional intelligence among parents irrespective of the condition of the child with ID .

Objective of Study

1. To assess and compare the gender difference in term of family burden between parents of child with intellectual disability.
2. To assess and compare the gender difference in term of quality of life between parents of child with intellectual disability.

Research Methodology: The study was conducted at Kalyanam Karoti, a non-governmental registered organization , approved by rehabilitation council of India, based on teaching, training and rehabiltaton, located at Kalyan Dham, Masani –Delhi Link Road, Swaraswat Kund, Mathura, Uttar Pradesh (UP).The study was conducted between the periods of July 2019- October 2019.

Sample

400 samples were recruited in the present study. The two hundred children with intellectual impairment (IQ=40 to 70) and 200 parents (100 male and 100 female) were selected on the basis of their availability and purposive sampling techniques.

Inclusion Criteria for parents of Children with Intellectual Disability:

1. Parents of mentally challenged children (diagnosed as mild to moderate mental retardation).
2. Parents who were able to comprehend the instructions.
3. Parents who gave consent to participate in the study.
4. The parents who were living with the child with Intellectual functioning (I.Q. between 70-40).
5. Participants have at least primary education

Exclusion Criteria for parents of Mentally Retarded Children

1. Parents who had more than one mentally retarded child (diagnosed as mild, severe and profound level of mental retardation, having any co-morbid condition like cerebral palsy, mental illness, and vision or hearing impairment).
2. Parents having psychiatric illness and physical illness.
3. Parents refuse to give informed consent.

Design

The study was cross-sectional.

Tools

Inform Consent Form and Socio-demographic and Clinical data Sheet: A consent form and socio-demographic record sheet was prepared for taking the written inform consent and collecting the information about various areas of social, demographic and clinical variables. Information relating to age, sex, residence, marital status, education, types of family, occupation, age of child, level of intellectual impairment of child were recorded in as structured interview setting and the investigator recorded the information.

1. **Socio-Demographic Data Sheet:** It contains information about socio-demographic variables like age, sex, religion, education, marital status and domicile which is semi-structured, self-prepared Performa especially drafted for this study.

1. **Seguin Form Board Test (SFBT):** In 1856 Seguin developed a simple performance-based intelligence test using form boards to evaluate eye–hand coordination, shape concept, visual perception, and cognitive ability through nonverbal means. It is used to assess the participants' motor dexterity, visuomotor coordination, spatial organization, and speed and accuracy of performance, and can be used in children as young as 3 years . The form board consists of 10 different wooden shaped blocks, and the participants are required to fit the differently shaped blocks into their respective slots on the form board. This test administered in three trial and the best time from three trials was used to determine a mental age from the standard chart, which was subsequently used in determination of the intelligence quotient (IQ) [18].
2. **Family burden interview schedule (FBIS):** This

is developed by Pai and Kapur in 1981. This scale is widely used to measure caregiver stress of those who are performing care giving activities of any family member with any chronic illness. It measures both subjective and objective burden of caregivers. This is a semi-structured interview schedule comprising 24 items grouped under six areas viz. financial burden, disruption of routine family activities, family leisure, family interactions, effect on physical and mental health of others. Rating of burden is done on a three point scale for each item and a standard question to assess the 'subjective' burden is also included in the schedule. The validity and reliability of the scale has been shown to be satisfactory. The inter-rater reliability for all items was reported to be more than 0.78 by the authors of the schedule [19]

3. **Quality of Life Scale (WHOQOL-BREF., Hindi version):** Hindi version of the WHOQOL-Brief has been derived from the original World Health Organization Quality of Life Scale. The Hindi version WHOQOL-Brief Scale is adopted by Saxena et al. (1998). WHOQOL-Brief is a short version of WHOQOL-100 questionnaires. WHOQOL-Brief has been tested in 15 centres including New Delhi and Chennai from India. WHOQOL-Brief contains 26 questions in 4 major domains (i.e. physical health, psychological health, social relationships and environment) to measure the quality of life. This scale emphasizes subjective experiences of the respondents rather than their objective life conditions[20].

    1. **Psychological domain** – measures the self-perception and cognitive ability
    2. **Physical domain** – measures physical problems like joint pain, hearing, vision and sleep difficulties
    3. **Social domain** – measures the level of social life, personal relations, social support, family acceptance and social interaction
    4. **Environmental domain** – measures living conditions, security, availability of medical assistance, opportunity of recreation and facilities.

Procedure

A total 200 children with intellectual impairment and 200 parents of intellectual impaired children were selected for the study, those who fulfilling the inclusion criteria. After explaining the purpose of study to parents with their written informed consent was taken and then the actual administration of the study was started.

Statistical Analysis: The data was analysed with using SPSS 20 as per suitable analysis techniques including descriptive and inferential analysis.

Results

Table :1
Socio-demographic profile of parents of child with intellectual disability

Variable		Group	
		Frequency	Percent
Gender	Male	100	50
	Female	100	50
Category	Gen	77	38.5
	OBC	86	43.0
	SC	35	17.50
	ST	2	1.00
Education	10th	69	34.50
	12th	76	38.00
	Graduation & above	35	17.50
	Illiterate	2	1.00
Occupation	Self	85	42.50
	Government Job	34	17.00
	Study	07	3.500
	Others	74	37.00
Residence	Rural	60	30.00
	Urban	85	42.50
	Semi urban	55	27.50
Marital Status	Married	180	90.00
	Other(Widow/Widower)	20	10.00

: **Table 1a**

Discriptive analysis of age of parents,age of child and IQ level of child

Variable	Group	
	Father(N=100) Mean±SD	Mother(N=100) Mean±SD
Age of Parents	40.29±8.25	40.69±8.34
Age of Child	11.43±4.60	11.65±4.67
IQ level of Child	54.87±8.50	54.65±8.45

* Not Significant

Table 2

Quality of life among parents of child with intellectual disability.

Variable	Group		t
	Father (N=100)	Mother (N=100)	
Physical Health	23.21±4.77	21.09±5.41	2.93**
Psychological Health	21.53±4.54	20.03±4.98	2.22**
Social Health	10.39±3.14	9.62±2.30	0.93
Environmental Health	27.80±6.04	25.18±6.95	2.84**
Quality of Life	82.93±15.95	76.31±16.86	2.85**

Table 3

Family burden among parents of child with intellectual disability

Variable	Group		t
	Father (N=100)	Mother (N=100)	
Financial Burden	4.12±2.655	5.39±3.46	2.90*
Dis. Family Relation	3.16±2.15	3.87±2.28	2.28**
Dis. Family Leisure	3.24±1.94	2.98±1.36	1.03
Dis. Family Interaction	3.58±2.51	3.78±2.12	2.03
Eff. on Physical Health	1.42±1.10	1.85±1.38	2.62*
Eff. on Mental Health	2.08±1.67	2.57±1.39	2.52*
Family Burden	17.34±7.85	20.50±9.70	2.53**

Discussion

The socio-demographic findings of the present study indicated that the sample was equally divided (Male=50% & female= 50%).In category variable 38.50% respondents belong to general category and 43% respondents belong to OBC category. In education variable 34.50% educated up to 10th standard, 38% educated up to 12th standard and 17.50% educated up to graduation and above level. In the residence variable 30% sample belongs to rural background, 42.50% were urban and 27.50% were sub-urban. Occupation-wise distribution indicated that 42.50% samples have self-occupation, 17% have government job and 37% were other.

The discriptive analysis of the varaibles between two groups (Table 1a) disclose that mean age of the respondents of male child was 40.29±8.25 and respondents of female child was 40.69±8.34. Age of the male child found as mean value of 11.43±4.60 and female child 11.65±4.67. The intellectual functioning of male child the mean value 54.87±8.50and the value of female child was 54.87±8.50.There were no significant difference has been found between parents in the area of age of parents, age of child and intellectual functioning of child.

The main aim of the present study was to assess the quality of life and severity of family burden of parents with intellectual impairment. In present study table 2- shows about the Quality of life among parent of mentally challenged children. The mean score of Physical health of father is 23.21±4.77 and mother is 21.09±5.41. The t value of Physical health is 2.93 and it is most significant at 0.01 levels. The mean score of Psychological health of father is 21.53±4.54 and mother is 20.03±4.98. The t value of Psychological health is 2.22 and it is significant at 0.01 levels. The mean score of Social health of father is 10.39±3.14 and mother is 9.68±2.30. The t value of social health is 0.93. The mean score of Environmental health is 28.31±6.09 and mother is 26.26±5.88. The t value of environmental health is 2.41and it is most significant at 0.01 levels. The mean score of Quality of Life of father is 84.47±14.61 and mother is 78.87±14.62. The t value of Physical health is 2.85 and it is most significant at 0.01 levels. The findings of this study indicated that father with Intellectual Disability have had better quality of life in comparison the mother with ID, especially in the area of physical health, psychological health and environmental health. Previous findings also support to the present findings. Mothers of children with intellectual disability showed to have deteriorated physical health, psychological state, the perception of the environment, and impaired social relationship while comparing to the mothers of healthy children (Dogar et. Al; 2012).While a recent study has been conducted in Muzafferpur, Bihar showed that both the parents either mother or father showed an equal level of qualty of life and family burden (Rathi; Kumar & Singh; 2017).Another findings of the previous studies highlighted that QOL of parents with intellectually disabled children will have to face a major challenge during their child's transition from childhood to adulthood. High demand for caring needs, support services, and low spiritual faith can result in poor QOL of parents (Bertelli et. Al.; 2015) .Lloyd & Hastings(2009) found that dimensions of psychological wellbeing such as anxiety, depression and stress of mothers are affected by lower levels of hope and more behavioural problems of the child. Higher hope will help in developing a positive effect and enhanced psychological wellbeing. Developing a hope among the mothers will aid improving the psychological wellbeing. Mothers had scored higher on quality of life in environment domain when their MR Child had the ability to do judgement in daily living.The father's involvement in the lives of their young children with severe intellectual disability was highest in the areas of playing, nurturing, discipline and deciding services (Simmerman; Blacher & Baker; 2015). In another study,it has been seen that family with ID have poor quality of life in the several domains of the QOL (Bohem; Carter & Taylor ;2015).

Table 3. Showed that the mean difference of family burden of both the parents . Mother had perceive more financial burden in comparison to father. It has also found that Disruption of family relation, Disruption of family leisure and Disruption of family interaction are poor in mother in comparison to father.. Effect on Physical Health and Effect on Mental Health are better of father in comparison to mother. The score of family burden indicate that mother face more burden in compare to father. Briefly we can say that there is significant difference between males and females as caregivers of intellectual impaired children in quality of life and various dimensions of family burden . Mother has high level of family burden and poor quality of life in comparison to father, while a recent study has done in muzafferpur, Bihar emphasized that both parents showed an equal level of family burden and quality of life (Rathi; Kumar & Singh; 2017).Panday R &Fatima N(2016) have also found that direct relationship between the degree of perceived burden, social emotional burden, disruption of family routine and disturbance in family interactions for women with intellectually disabled children rather than men. The present findings also supported by a study done by Singh K et al (2016) in which mothers of children with ID displayed lower physical health, impairment in social relationships, in their psychological state and poorer perception of their environment . It has also seen that significant gender difference in the area of perceived stress among parents with I D and mothers have perceived more stress than father (Verma; Srivastava & Kumar; 2017).Lin et al. (2009) found the reduced quality of life of caregivers of children with intellectual disabilities, which are caused by factors such as health of caregivers, family income and the stress caused by a lack of social supports . Norlin, D., & Broberg, M. (2013) also observed in their study that also found that mothers with children having intellectual disability showed low wellbeing and poor marital and couple QOL. It has found, good to the excellent QOL among parents of children with intellectual disability availing respite care (Caples & Sweeney; 2011). Social support of parents of children with intellectual disability have poor in comparison to parents of normal children and poor social support influence the quality of life of parents(Kumar; Ranjan & Panday ; 2019).It has observed that parent training programme of individual with intellectual disability is effective in enhancing quality of life dimensions income, access and maintenance of Individual with Intellectual Disability. That provides parents knowledge, guidance and understanding about their children and ways how to respond them in a positive, nurturing and proactive manner.(Paswan A.D.& Kumar P, 2021)

Conclusion

The goal of the present study was to examine the quality of life and family burden across the gender. Overall, on the basis of results the message is conveyed that the effective and sustainable psycho-social programs are needed to provide necessary support for the special needs of the children and their families(Specially mother)should support from health and psychosocial professionals in care and coping with.

The results of this study can have large practical implications. Parents should be provided with individual and group support in coping with the everyday challenges. Individual counseling will help them in development of competences for parental role and empower them to advocate for the rights of their children. As the mothers are more vulnerable in this sense, they should be a priority for support provision. The position of mothers can be facilitated with additional financial resources from the state, which will help in getting a better childcare and better child treatments. Mothers should also have some benefits regarding their employment status in the sense of flexible working hours. The efforts of mother of children with intellectual disability should recognize by society. It is time to accept the challenges and responsibility, specially the mental health professionals and special educators and provide care to this vulnerable as well as needy population. These finding must be taken into account in policy making to provide better and more specific support and interventions for parents of children with intellectual disability.

Limitations

First, the sample size is small and generalization of the present findings should take into consideration. We need a large sample to validate the findings of this study. This is a cross-sectional study that does not allow us to find causal relations. More variables could be included to understand the relationship between various variables better.

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Conflicts of interest: There are no conflicts of interest.

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