
Parents of Intellectually Disabled Children: A Study of Their Psychosocial issues

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1. INTRODUCTION

Prevalence of mental illness has a significant impact on the global burden of diseases. Among the urban population of developing countries, 5.3% are suffering from mental illness (Deswal, & Pawar, 2012). Intellectual disability or mental retardation as it persists throughout lifetime adds on to these rates. It contributes to 1.2% of the mental illness in Kerala (Celine, & Antony, 2014). Intellectual disability is the most prevalent childhood psychiatric disorder. Among them, majority of the cases (85%) belong to mild mental retardation (Harris, 2009), (Ganguly, 2000).

A Meta-analysis on the prevalence of intellectually disabled children shows that 10.37/1000 population are affected (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 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.

Mental retardation is a highly prevalent and highly disabling condition. Depending on the severity of their disability, mentally retarded (MR) are more and more dependent on their caregivers. Previous studies have focused either on positive or negative impact on

the parents. In this study an attempt has been made to assess both positive and negative impact on the parents of such persons so that they could be helped to manage these problems in the best possible way.

Recent studies of care giving have focused on the term, burden. The term, family burden, was mentioned first by Grad and Sainsbury. They defined it as the negative expenditures created by the intellectually disabled children for their families. Intellectually disabled children significantly affect how their families live. Deficiency becomes the core of families' lives upon diagnosis and causes them many burdens. Family members' roles and responsibilities start to change. These changes may be seen in intra familial roles, private living spaces, social environments, expectations, plans and careers. Factors such as economic and educational status, profession, marital adjustment and cultures of the parents, lack of social support, difficulties in communication, severity of the disease, children's age, distortions of family routines, the level of need for medical aid and the financial burden caused by the disease all affect the stress levels of parents. 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.

2. DEFINITION OF DISABILITY AND MENTAL RETARDATION

Disability may be defined as disturbances in performance of social roles that would normally be expected of an individual in the habitual milieu, arising in association with diagnosable mental disorder. The terms disability, impairment, and handicap are often used in a confusing and interchangeable fashion. Recently, the World Health Organization has given the following

Definitions:

Impairment is an anatomical defect, or absence or loss of a specific psychological or physiological function that can arise from a disease or from an intrinsic pathological state...

A. Disability is a restriction in the ability to perform a task or activity within the range normally expected of someone of the same age or level of maturity.

B. Handicap is a social disadvantage preventing the fulfilment of a normal social role.

Objectives

To study the socio-demographic profile of parents of intellectual disabled children

1. To assess the psychosocial issues of parents of intellectual disabled children
2. To study the financial issues of parents of intellectual disabled children
3. To study the tanning and welfare related issues of parents of intellectual disabled children

3. STATEMENT OF THE PROBLEM

Parents who have intellectual disabled child may be closely scrutinized for any sign or symptom of abuse or neglect to their children. Parents live in fear of having their children taken away. Many others are not identified as having an intellectual disability and try to hide their disability, depriving themselves of any opportunity for accommodations. For those parents whose children have been taken from them, the reunification plan usually requires parents to attend counselling sessions and parenting classes that are not cognitively adapted.

4. OPERATIONAL DEFINITIONS

1. Parents : Biological parents

2. Intellectual disability : Intellectual disability [Intellectual disability disorder] is a disorder with onset during the development period that includes both intellectual and adoptive functioning deficits in conceptual, social and practical domains [DSM-V]

3. Children: Children who are the below 18 years old.

5. METHODOLOGY

Research Design: Descriptive research design adopted for the study.

Sample: Sample size is 50. 25 Male and 25 Female: Either two parents or single parent will be recruited for the study by using purposive sampling method. The parents of intellectual disabled children who meet the following inclusion criteria will be included.

Inclusion-Exclusion criteria for Parents

a) Inclusion criteria

- Persons of intellectual disabled children diagnosed as per ICD-10 by psychiatrist.

b) Exclusion criteria

- Parents with any clinical emergency
- Parents having any other co-morbid neurological illness

Universe of the study: Parents of intellectual disabled children seeking out patient care services of Dharwad Institute of Mental Health and Neuro Science [DIMHANS], dharwad, Karnataka is considered as the locale of this study.

Tools: The following tools used in the present study:

Primary Data

1. Socio-demographic Data sheet: It was developed by the researcher to collect the specific socio-demographic and clinical variables such as age, gender, education, occupation of parents, income and level of intellectually disability of children-.
2. Data were collected with the help of an interview schedule

Secondary of Data

Various statistical tools were used to analyze the secondary data. Observation, web search by referring various government publications and reference book, journals, published data from time to time .Research of journals, periodicals, technical materials, electronics /internet search, site visits etc.

Data analysis

Table 1: Demographic profile of the Respondents

Demographic characteristics	Options	Frequency	%
Age	1. 18-35	22	44
	2. 36-50	26	52
	3. 50above	02	04
Sex	1. Male	25	50
	2. Female	25	50
Educational Qualification	1. Illiterate	17	34
	2. Primary school	14	28
	3. Secondary school	17	34
	4. UG/PG	02	04
Marital Status	1. Married	44	88
	2. Divorced/ Deserted	06	12
Religion	1. Hindu	34	68
	2. Muslim	16	32
Type of Family	1. Joint	03	06
	2. Nuclear	47	94
Occupation	1. Agriculture	17	34
	2. Government Employee	03	06
	3. Business	03	06
	4. Unemployed	27	54
Residence	1. Rural	36	72
	2. Urban	14	28
Income	1. Below 5000	10	20
	2. 5001 to 10000	15	30
	3. 10000 Above	25	50
	Total	50	100

- Above the Table shows that majority of the respondents are within the age of 36-50 years (52%) only (4%) of the respondents are within the age of 50 above
- The Majority of the respondents education 34% of the illiterate and secondary education are same and (2%) of the respondents are UG/PG.
- Majority of the respondents are married (88%) and (12%) of the respondents are divorced/deserted.
- The Majority of the respondents are (68%) Hindu and (32%) Muslim
- Majority of the respondents are belongs to the nuclear family (94%) were as (6%) of the respondents are belongs to joint family. Therefore majority of the parents living in nuclear family therefore they have take more responsibility towards there intellectually disabled children.
- Majority of the respondents are unemployed (54%) only and (6%) of the respondents government employee and business.
- Majority of the respondents are lived in (36%) of Rural and (14%) respondents live in urban.
- Majority of the respondents family income (50 %) of 10000 above

Table 2: Psycho-Social issues

Variables	Characters	Frequency	Percentage
Was your child healthy during nurturing after baby birth?	Yes	34	68
	No	15	30
	I don't know	01	02
Did you feel sad about child disability?	Yes	41	82
	No	09	18
	I don't know	00	00

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Do you feel stress to care your child every day?	Yes No I don't know	37 13 00	74 26 00
Do you take a baby out of the house every day?	Yes No I don't know	31 19 00	62 38 00
Do you feel embarrass going with your baby to attend social programme?	Yes No I don't know	07 43 00	14 86 00
Have you ever faced criticism in society due to child 's disability?	Yes No I don't know	15 35 00	30 70 00
Do you leave your baby playing with neighbours?	Yes No I don't know	23 27 00	46 54 00
Have you ever noticed that other people or kids would be reluctant/hesitate to play with your baby?	Yes No I don't know	14 36 00	28 72 00
Can you able to handle your child's behaviour?	Yes No I don't know	39 11 00	78 22 00
Do you know about the nature of your baby's disease or illness?	Yes No I don't know	47 2 1	94 4 2
Do you feel sad because your child's intelligence is low?	Yes No I don't know	43 7 00	86 14 00
Does the doctor or psychiatric experts provide information about the nature of child's illness?	Yes No I don't know	45 5 00	90 10 00
Do you feel that your baby's disease is completely cured by doctor's medicine?	Yes No I don't know	45 5 00	90 10 00
Are you experiencing anxiety in the form of childhood illness every day?	Yes No I don't know	32 18 00	64 36 00
Mental retardation is a state of stagnant growth in the brain. Do you agree?	Yes No I don't know	46 4 00	92 8 00
Do you feel that there are drugs that can decrease child's MR and increase intelligence?	Yes No I don't now	13 17 20	26 34 40
Do you know that if you get married in blood relationships, there will be possibility to give birth mentally retarded child?	Yes No I don't know	46 3 1	92 6 2
Are you sending your child to any special school?	Yes No I don't know	7 43 00	14 86 00
Do you any family disputes because of having intellectual disabled child?	Yes No I don't know	03 47 00	06 94 00
Child becomes intellectual disabled child due to injury at the time of birth?	Yes No I don't know	22 4 24	44 08 48
Mental retardation comes due to infection during birth of child..	Yes No I don't know	16 04 30	32 08 60
	Total	50	100

- Majority of 68% of the respondent told child healthy during nurturing after baby birth is good and 2% of the respondents they have given the respond is not healthy.
- Majority of 82% of the respondents said feel sad their regarding child disability remaining 18% of the respondents said no feel sad their regarding child disability.
- Majority of 74% of the respondents they accepted they feel stress to concern their children and 26% of the respondents they didn't accepted.
- Majority of 62% of the respondents they will take them their child to come out the home every day and 38% of the respondents they have hesitating to take their baby to outside the home.
- Majority of 86% of the respondents of the parents feel embarrass to attend the social programme with their baby and 14% of the respondents they didn't embarrass.
- Majority of 70% of the respondents they have faced criticism from society and 30% Of the respondents they didn't criticised.
- Majority of 54% of the respondents they didn't leave their children's playing with neighbour and 46% of the respondents they left their children to play with neighbours.
- Majority of 72% of the respondent they didn't noticed by other peoples didn't play with your baby and 28% of the respondent they agreed they have noticed by other people.
- Majority of 78% of the respondent they able to handle their child behaviour and 22% of the respondents they couldn't able to handle their child's behaviour.
- Majority of 94% of the respondents they have aware about their babies' illness nature and 2% of the respondents they didn't aware of their child disease.
- Majority of 86% of the respondents they have disappointed about their child's intelligence is low and 14% of the respondents they didn't disappointed.
- Majority of 90% of the respondents explore their information regard psychiatric suggestions regarding their child illness nature and 10% of the respondents they have uninformed.
- Majority of 90% of the respondents opinion is doctor's medicine will cure their babies disease and 10% of the respondents they didn't agree.
- Majority of 64% of the respondents they badly experiencing anxiety in the frame of their child's illness and 36% of the respondents they didn't feel this kind of experience.
- Majority of 92% of the respondents they have given their opinion regarding mental radiation is a state of stagnant growth in the brain and 8% of the respondents disagree.
- Majority of 40% of the respondents they didn't accept the drugs didn't decrease the child's MR and increase intelligence and 26% of the respondents they have accepted.
- Majority of 92% of the respondents they have accepted marriages in blood relationship possibility to birth of MR Child and 2% of the respondents they didn't reacted properly.
- Majority of 86% of the respondents they are didn't sending their child to any special school and 14% of the respondent sending their child to special school.
- Majority of 94% of the respondents they didn't agree the family disputes is not major issues to having a MR Child and 65 of the respondents they considered.
- Majority of 48% of the respondents they don't know the regarding disable child injury at the time of birth and 8% of the respondents they didn't agree.
- Majority of 60% of the respondents unaware about MR comes due to infection during birth and 8% of the respondents they didn't agree.

Table 3: *Financial issues*

Variables	Characters	Frequency	Percentage
Do you feel more financial burden to take care your child?	Yes	34	68
	No	16	32
	I don't now	00	00
Can you able to fulfil your child's basic needs?	Yes	39	78
	No	11	22
	I don't now	00	00
Do you face any financial difficulties to buy special equipment for your child?	Yes	44	88
	No	4	8
	I don't now	2	4
Do you face financial difficulties to meet doctors often for yours child treatment?	Yes	34	68
	No	16	32
	I don't now	00	00
Currently, Do you have financially problem in the family?	Yes	48	96
	No	2	4
	I don't now	00	00
If, yes did you take a loan from somebody to for treatment?	Yes	23	46
	No	27	54
	I don't now	00	00
Do you feel burden for your family members to take care the child?	Yes	45	90
	No	05	10
	I don't now	00	00
Total		50	100

- Majority of 68% of the respondents they suffering from financial burden and 32% of the respondents they didn't agree.
- Majority of 78% of the respondents they are fulfilling their child basic needs and 28% of the respondents didn't fulfilling their child basic needs.
- Majority of 88% of the respondents facing financial difficulties to consume the special equipment for their child and 4% of the people unaware.
- Majority of 68% of the respondents they get difficulties to meet doctors due to financial issues and 32% of the respondents are negatively.
- Majority of 96% of the respondents currently facing the financial problem in the family and 4% of the respondents are disagree.
- Majority of 54% of the respondents they didn't take any loan for their child treatment and 46% of the respondents they loaned.
- Majority of 90% of the respondents they feel burden for family member to take care the child and 10% of the respondents didn't accepted.

Table 4: *Training issues*

Variables	Characters	Frequency	Percentage
Are you able to train your child as expert's suggestions?	Yes	23	46
	No	27	54
	I don't now	00	00
Can your child be able to train as told by experts?	Yes	22	44
	No	28	56
	I don't now	00	00
Do you know that skills of child may be enhanced if you follow experts said?	Yes	16	32
	No	34	68
	I don't now	00	00

Has any child's functionality been changed as experts said?	Yes	03	6
	No	47	94
	I don't know	00	00
Do you think your child needs more training?	Yes	35	70
	No	15	30
	I don't know	00	00
	Total	50	100

- Majority of 54% of the respondents negatively reacted to train their child experts suggestions and 46% of the respondents are agreed.
- Majority of 56% of the respondents didn't agree to trainers through able the child and 44% of the respondents they follow the experts training.
- Majority of 68% of the respondents seriously disappointed about experts guidance and 32% of the respondents they following the experts suggestion.
- Majority of 94% of the respondents they didn't recovered by experts therapy and 6% of the respondents are convinced.
- Majority of 70% of the respondents they have agreed training is most important for their child and 30% of the respondents they didn't agree.

Table 5: Welfare issues

Variables	Characters	Frequency	Percentage
Does your family receiving available government facilities child?	Yes	37	74
	No	13	26
	I don't know	00	00
Are you receiving monthly pension every month?	Yes	36	72
	No	14	28
	I don't now	00	00
Have you received a railway concession certificate?	Yes	24	48
	No	26	52
	I don't now	00	00
Do you have lack of information about getting these above facilities?	Yes	04	08
	No	46	92
	I don't now	00	00
Do you know that there are special schools for intellectual disabled child?	Yes	30	60
	No	19	38
	I don't now	01	02
Have you made any insurance policy for your child's future?	Yes	02	04
	No	48	96
	I don't now	00	00
Do you know about Niramaya scheme?	Yes	01	02
	No	49	98
	I don't now	00	00
	Total	50	100

- Majority of 74% of the respondent's families receiving government facilities and 26% of the respondents didn't receiving.
- Majority of 72% of the respondents consume their monthly pension and 28% of the respondents didn't able to receive the pension.
- Majority of 52% of the respondents they didn't received railway concession certificate and 48% of the respondents they used properly.

- Majority of 92% of the respondent's lack of regarding to getting facilities of government and 8% they have aware.
- Majority of 60% of the respondents aware of special schools and 2% of the respondents are unaware.
- Majority of 96% of the respondents they didn't get any insurance policy for their child future and 4% of the respondents are fully agreed.
- Majority of 98% of the respondents they didn't get any information regarding Niramaya scheme and few percent know this scheme.

6. SUGGESTIONS

1. Promotion of psychosocial counselling should be practice in respondents their family and social life.
2. Professionals need to collaborate with parents of children with ID in their provision of services, support parents in gaining knowledge about available services and involve them in decisions about services. This may improve both parents' control over services and parental self-efficacy Government should decrease the medical treatment cost those who have ID Child and sanction or grant a medical leave should extend take care of their ID Child properly.
3. Some special centre or remedial schools should be activate and rehabilitees the child. Some special training through enhance the quality life and mental health cooperation and public participation to implement the government policy and scheme.
4. Social services need to support the families to find community-based recreational activities for their children and to improve their ability to facilitate access to such activities. Leisure activities for children will also provide parents some time for themselves.
5. Social services and paediatric facilitation units should establish parent support groups for families of children with mild ID, so that families can exchange experiences and advice. Through these networks they may become more aware of available services and their effectiveness, as well as building informal networks that may reduce dependence on service systems.

7. CONCLUSION

Based on this study, the findings convey that most of the parents do not have good psychological well being due to their multiple responsibilities. To improve their psychological well being the parents of intellectually challenged children should undergo therapies such as psychotherapy, relaxation and stress management techniques. And it also applicable to the family members of the intellectually challenged children, referral services can also be given to parents and the family members to lead their life in positive way. Because referral service makes the parents to help their child in a better way. Based on the motivations and supports from the family members and the relatives are helps the parent to supports their child in a batter way and it also helps them to have a hope and confidence in their child's development through that this parents of children with intellectual and developmental disabilities help their child to have continues special training and rehabilitation. Proper counselling services are also helps the parent to lead their life in a positive way and it also helps them to have a good psychological well being.

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