

Resilience and Vulnerability in Parents of Child with Intellectual Disability (ID)

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ABSTRACT

Intellectual disability (ID) can be found around the world, an estimation 2 to 3% of population suffer with ID. Person with ID face difficulty in physical activities, social learning, motor activities in day to day life. This is not individual problem, it brings several other problems and affects individual with ID as well as people attach to him/her. Parents are intimate care giver to any child; therefore children with ID are also their responsibility. Parents face multiple difficulties in physical care, financial arrangement for treatment, social exclusion, social stigma etc. these difficulties expose them to several psychosomatic issues. So dealing with these psychosocial issues, we must need to understand parent's difficulties. Present study aims to lighten the positive and negative impacts on parents. This study targets parents of children with ID, studying in special school in Puducherry (UT). With help of structured tool, Mothers and fathers both interviewed. Mothers face more difficulties' compare to fathers and they found with high positive as well as negative impact. Mothers make high carrier adjustment and face loss of social support because of having child ID. Mothers observed with high resilience compare to male counter parts.

Key words: Intellectual disability (ID), Resilience, Vulnerability

INTRODUCTION

There are four major areas in typical development of a child 'physical development', adaptive behaviour, language & reasoning and social behaviour. A child without any kind of dysfunction can achieve these stages at expected ages. ^[1] In some cases children face difficulties to achieve mile stones on expected age. Intellectual disability (ID) is term used for children who learn and develop slower than typical kid. ^[2] Based on available data from 1% to 3% of total population have intellectual disability worldwide. ^[1,3] Intellectual disability is defined as significantly low average intellectual functioning, connected with major deficit or impairment in adaptive learning, which manifests during

developmental period. ^[4] Children with ID vary in their behavioural, psychological, physical and social characteristics as much as so called 'typical' population does. ^[1] Family is primary institution where child start learning and developing, so impact of disability on family determines whether the child has to develop or not. ^[4]

Intellectual disability is a marker given to a individual who has IQ (Intelligent Quotient) score 70 or less. ^[3] ID can classify into four types based on IQ scores. ^[1] Those four types are mild (50-70 IQ), moderate (35-49 IQ), severe (20-34 IQ) and profound (less than 20 IQ). However, it does not affect only performance on tests but also put margins on one's ability of personal care,

language, interactions and occupational skills.

Now day families and community importance is increasing in care of children with ID rather institution [5] treatment or care is preferred in family at home. Family have pivotal role in child care, and parents are main source of care in family. Parents are facing multiple difficulties in child care because they are getting least support from community due to social stigma, cultural myths etc. and another side institutional help reduced. Therefore utmost impacts of child's disability are faced by parents. [6] The inconveniences faced by parents are psychological problems, sociological problems, and economic problems. All impacts are likely to affect entire functioning of parents, which hold back their coping mechanisms. [7]

Birth of new child is rejoicing and celebration in a family. Parents have many dreams and aspirations for their newly born child, but birth of a child with ID ruined their dreams and expectation, can traumatic and shocking affair for family. Feeling of anguish and loss that family perceived is result by insight that imagined typical healthy child they had waited for nine months was certainly not born. There are plenty of evidence that family members practice a variety of emotions in reaction to identification of ID in their child, including denial, disbelief, irritation, anguish, guiltiness, shame, depression, withdrawal, ambivalence and terror of stigma. [3]

In Indian culture, there is much emphasis on religious beliefs, therefore mostly families perceive the event optimistically or pessimistically that they are either blessed or punished by God. They feel that is result of their past deeds. Even children with ID are seen as punishment of God. [3] Sometimes such children are left on to mercy of God and are not provided appropriate facilities for their recreation and rehabilitation [8] which hurdle their development and abilities.

In Indian society and family system mothers have responsibility to take care of

child. When they take care child with ID might face several difficulties, which may affect her social, emotional, personal and psychological conditions. Affects can be negative as well as positive. Difficulties can be in physical care of child, health issues, financial difficulty in child care, career adjustment, loss of support system, social restriction, feeling of embarrassment and ridicule, negative effect on relations. [3] Positive impacts may be improve in patience, tolerance, empathy, sensitivity, supports, batter relationship because of difficult conditions.

Physical and psychological traumas are expected when a mother take care of a child with ID, who cannot perform their physical and social activity independently. [8] Sometime families also get specific thoughts like suicide, separating child from family, removing reproductive organs in case of girl child or some time killing child. These conditions can be because of extra care of child or in same time loss of support from husband or family side. [9]

Family is a social institution and is one of the primary functions of society that is shaped by common agreements of male and female. As other institution this social institution also has some duties like giving birth to a child, taking care of child, teaching social behaviour, education etc. Therefore family is teaching and looking after children, developing good communication between family members and helping their child to perform independently. Even if child is intellectually challenged, he or she is one of the family members. When a family have child with ID than all family members have impacts on them including siblings. In such condition all family peace trouble and all family members focus on differently able child. Parents blame themselves or blame each other disability, arguments start from blaming and some time result in separation, divorce, psychological and social problem. [5] This study aims to understand the impacts on parent because of having child with ID.

METHODOLOGY

Present study was conducted with mothers and fathers of children with ID who was studying in Satya Special School Puducherry. Parents (both mother and father) of 40 children with ID were approached for interview. From that 65 parents participated, 36 were mothers and 29 were fathers. Parents of children with ID only included for study other disability like down syndrome, autism, learning disability were excluded. Inclusion and exclusion were made based on school records of children.

A structured interview schedule “NIMH DISABILITY IMPACT SCALE” was used for accessing the impact of children’s intellectual disability on parents. The tool was developed and validated by National Institute of Mentally Handicap Secunderabad, 2000. The tool is free for use and appropriate for achieving objectives. Author is master in medical and psychiatric social work and familiar with tools and associated phenomenon, therefore tool was adopted for this study. Interview was

conducted either in school or at their residential premises.

Data was coded and entered in SPSS sheet and analysed by using average, cross tabulation, and linear regression.

Ethical issues were taken care, study was explained to every respondent, which ever language (Hindi, English and Tamil) they were comfortable. After explaining about aim & objectives of study and assuring confidentiality, informant consent (written or verbal) were taken from all respondent. Study proposal was presented in department of Social Work and Pondicherry Central University, there it found ethically appropriate and approved for conducting this study.

RESULTS

The analysis was done in three levels, first level frequency and percentage were shown, second level cross tabulation was calculated and in third level linear regression was done. Total number of participants were 65, from that 44.6% were males parents and 53.4% were females parents.

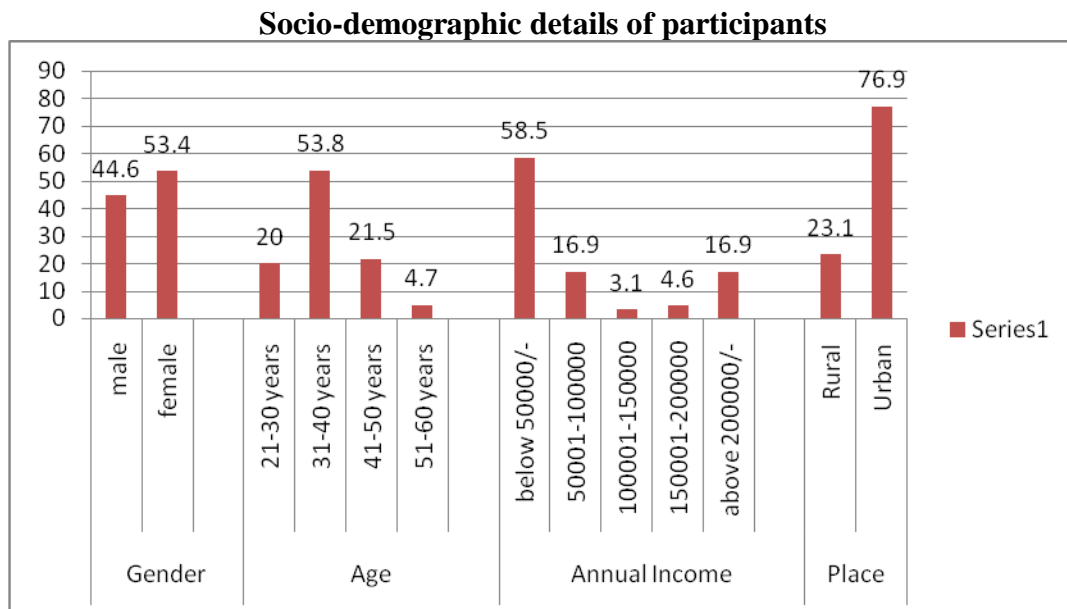


Fig. I

The 20% were belongs to 30 years age group and below, 53.8% were from 31 to 40 years age group, 21.5% were from 41 to 50 years of age group and 4.7% were

from 51 to 60 years of age group. The 58.5% participants income were below 50000/-, 16.9% of participants income was between 50001/- to 100000/- income, 3.1%

were having 100001/- to 150000/- income, 4.6% were having 150001/- to 200000/- income per annum, 16.9% were earning

200001/- and above per annum. The 23.1% participants were from rural area and 76.9% belonged urban area of Pondicherry.

Affects of children’s intellectual disability on Mother and Father

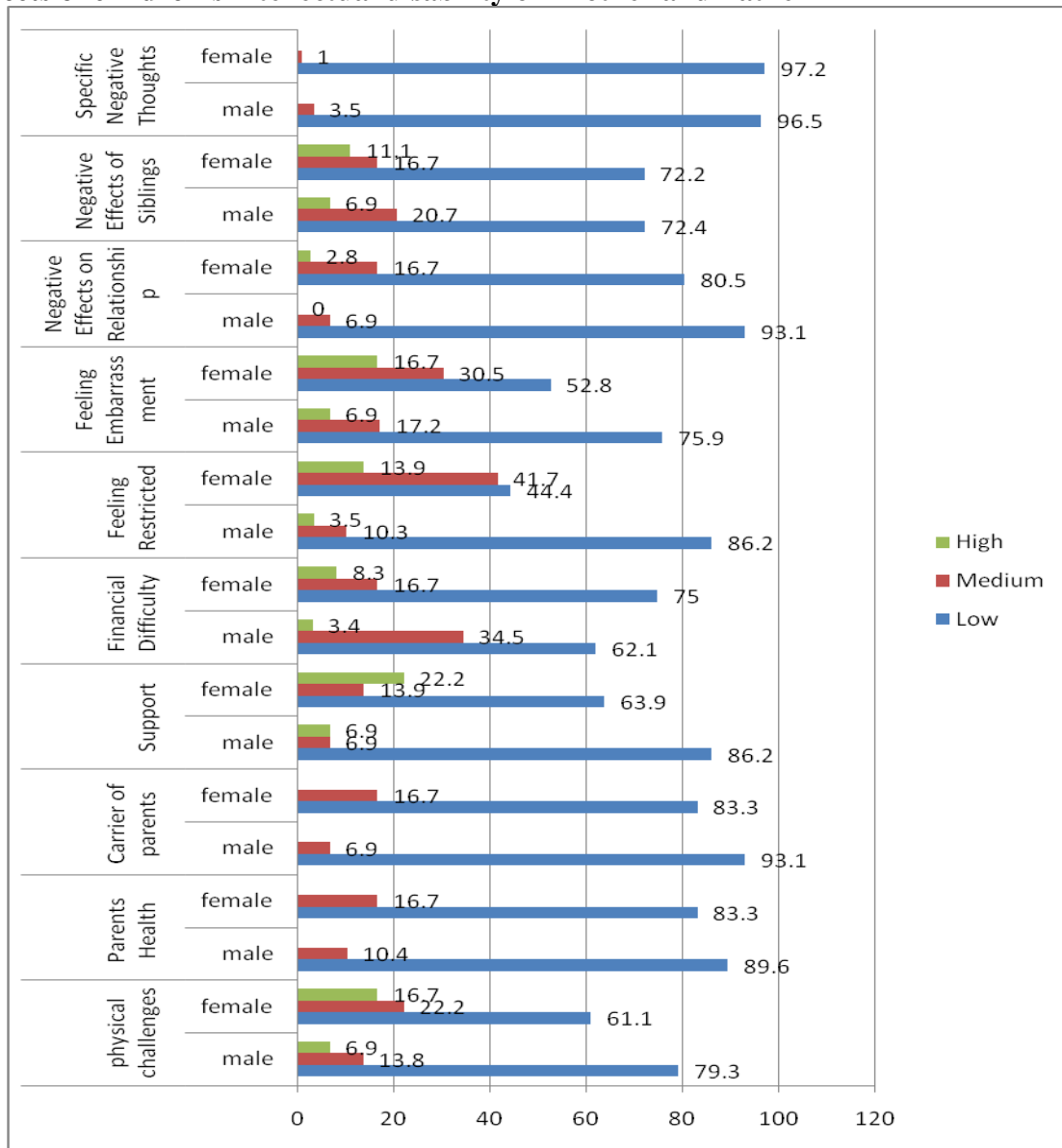


Fig. II

The fig. II is showing differences of impacts on mothers and fathers being with their children who are having intellectual disability. Fig. II shows 6.9% fathers face lot of difficulties in physical care (Bathing, Feeding, Dressing, Toileting, Brushing, Grooming, Lifting, Carrying and Medicating) of child, 13.8% sometimes face difficulty and 79.3% do not face any difficulty in physical care of child. Compare to Fathers, 16.7% of mothers face lot of

difficulties in physical care of their child with ID, 22.2% mothers reported sometimes face difficulty and 61.1% reported no difficulties in physical care of child. Fig. II Shows 10.4% fathers reported some time they face health problem (Asthma, BP, Sleeplessness, Headache and Mental Worries) due to their child and 89.6% reported not facing any health issues due to their child with ID. The 16.7% of mothers reported sometimes they face health

problems due to their child which is higher than fathers, and 83.3% mothers reported that they don't face any health problems. The 93.1% of fathers reported no career adjustment and 6.9% responded sometimes they do career adjustment. and no father reported most of time adjustment in their carrier opportunity, compare to that 83.3% of mothers reported no career adjustment and 16.7% mothers face some career adjustment because of having child with intellectual disability. The 86.2% fathers reported no loss of social support (Spouse, Family, In-Law, Relatives, Friends and Neighbour), 6.9% some times and 6.9% fathers reported most of time loss of social support, compare to that 63.9% of mothers experience loss of social support, 13.9% some times and 22.2% mothers reported most of time they face loss of social support.

The 62.1% fathers reported no financial difficulty (In Visits to doctors, Transportation, Medical investigation, Aids, appliances, visits to traditional healers), 34.5% fathers reported some financial difficulty and 3.4% fathers reported lot of financial difficulties, 75% of mothers reported no financial difficulties, 16.7% some financial difficulties and 8.3% mothers reported lot of financial difficulties. Fig. shows 86.2% of fathers reported no social restriction (From Attending social Function, Pursuing leisure, recreational activities and in learning opportunity), 10.3% fathers reported sometimes feeling of social restriction, and 3.5% fathers reported most of time feeling social restriction, compare to that 44.4% of mothers reported no feeling of social restriction, 41.7% mothers faced sometimes social restriction and 13.9% mothers reported most of the time they feel socially restricted. The 75.9% of fathers reported feeling no embarrassment (In Family, Relatives, Neighbourhood, Community etc.), 17.2% fathers some time they feel embarrassment and 6.9% reported mostly they feel embarrassed, another side 52.8% of mothers reported not at all embarrassed, 30.5%

reported sometimes feeling embarrassed and 16.7% reported most of time feeling embarrassed.

Study shown 93.1% fathers have no effect on their relationship (With Spouse, In-Law, Family, Relatives, Friends, Neighbour etc.) because of having child with Intellectual disability, 6.9% of reported somewhat affected relationship, compare to that 80.5% mothers reported no affect to relationship, 16.7% reported somewhat affected relationship and 2.8% reported relationship affected a lot because of having child with intellectual disability. The 72.4% fathers reported other siblings are not affected because of child with intellectual disability, 20.7% fathers reported siblings are somewhat affected and 6.9% fathers reported siblings are affected a lot compare to that 72.2% mothers reported other siblings are not affected because of child with intellectual disability, 16.7% mothers reported siblings are somewhat affected and 11.1% mothers reported siblings are affected a lot. The 96.5% fathers reported no specific negative thoughts (Killing child, Attempting suicide, Restricting Family Size, Separating child from Family), 3.5% fathers reported sometimes they get negative thoughts compare to that 97.2% of mothers reported they are not getting any negative thoughts because of having child with intellectual disability and 2.8% reported sometime they are getting negative thoughts.

Fig. III show that 89.6% of fathers shown no or very low difficulties because of having child with intellectual disability and 10.4% of fathers reported Medium level of difficulties, Compare to that 75% of mothers reported low or no difficulties in caring a child with intellectual disability, 19.4% Mothers reported medium level of difficulties and 5.6% of mothers reported high level of difficulties because of having child with intellectual disability.

Fig. III also shows positive effects, 17.2% of fathers shown low positive impact (More Patience, More Tolerance, More Empathy, More Sensitivity, More Support and Better

relationship), 41.4% shown medium positive impact and 41.4% fathers reported high positive impacts because of having child with intellectual disability.

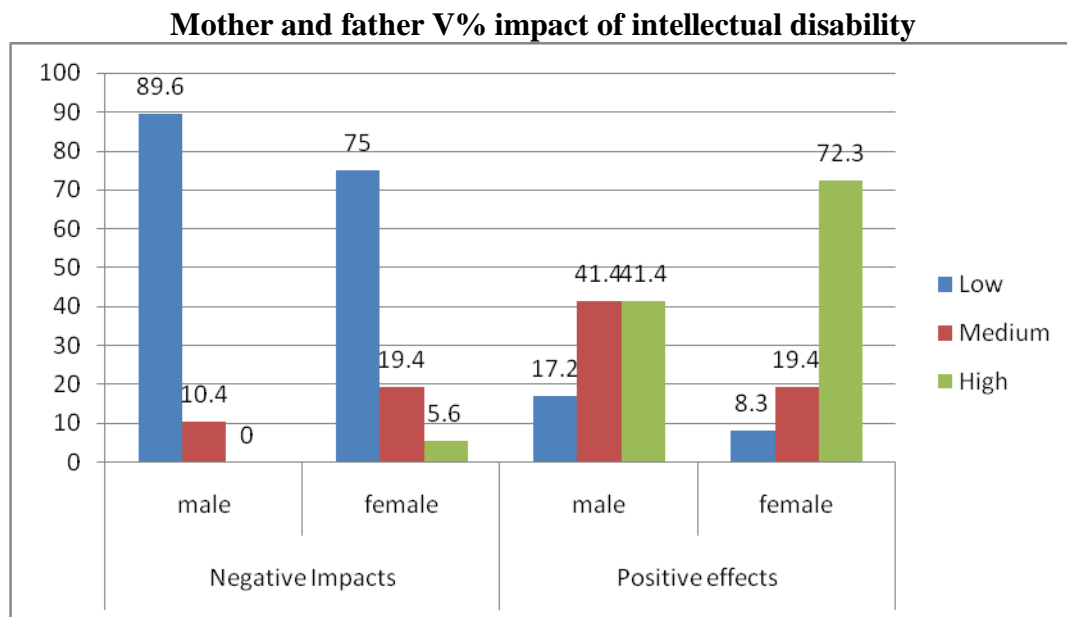


Fig. III

The 8.3% of mothers shown low positive impacts, 19.4% mothers shown medium level of positive impacts and 72.3% of mothers reported high positive impact because of having child with intellectual disability.

Regression Table

	Sum of Squares	Df	Mean Square	F	Sig.
Regression	1300.431	1	1300.431	8.553	0.005
Residual	9579.015	63	152.048		
Total	10879.45	64			
Predictors: (Constant), Gender of Parents					
Dependent Variable: Total score of negative impacts					
Regression	844.446	1	844.446	5.301	0.025
Residual	10035	63	159.286		
Total	10879.446	64			
Predictors: (Constant), Gender of Parents					
Dependent Variable: Total score of positive impacts					

Regression was run between negative impact as dependent variables and Gender of parents' independent variable. The mean score of negative impacts on parents is 20.7 and standard deviation is 13 in total negative impact. Regression result shown significance $P < .005$ (95% confidence interval) differences of negative impacts on mothers and fathers, it rejects null hypothesis. Gender (male and female) shown strong association with positive impacts of having child with ID. Regression results shown significance ($P < .025$) difference between mothers and fathers.

DISCUSSION

The results of this study displays gender of parents have significant impact; mothers are having both high positive and high negative impacts on them because of having child with ID. The reason for having high positive and high negative impact on mothers is because traditionally they are responsible to rare child. Child with ID have special needs, they need more care and time, which makes mothers to work more and harder. The status of second gender is another important factor, makes mothers to get vulnerable. Their status of second gender limits social mobility and social interaction, which affect their stress and

resilience. Most of daily activities of children are taken care by mothers irrespective of their social and working status. Because in Indian culture mothers are responsible for caring and rearing a child (he/she may be typical or special). Mothers do not get enough time for self care, because of their engagement with child. [10] Their day to day life is complicated and difficult which is strong associated factor of psychological and social issues. Caregiver burden is strongest predictor of psychological morbidity like depression and anxiety. [11] They are at high risk of common mental disorders, they score high in depression and anxiety evidences are in support. [12,13] Mothers are more prone to depression and others psychological problems [14,15] because of over involvement and social situation.

Mothers spend their most of time in caring of child and helping them in all physical care and social learning. [16] Because of that they do not get time for job, education or attending professional courses. Their career adjustment is again add on to unfulfilled desire or need, which further can be responsible for health and wellbeing conditions. Culturally fathers are not responsible for rearing child, so they continue with same role going outside home and earning. They enjoy more social relation and social interaction compare to mothers, which help them to release their stress. So having a child with intellectual disability does not much affect on father's career.

Mothers face double side triple type isolation, due to over involvement with child they do not get time to socialize, stigma of having child with ID stops them to socialize and cultural beliefs like child with ID is result of bad karma or sin makes people to avoid socialization. Even other family member also avoids socialization because of social stigma and associated cultural beliefs. Most of time mothers are considered culprit for giving birth to a child with ID, they blamed for that and face loose of support from family members. Having

child with intellectual disability, can a cause for family dysfunction breaking social support. [16] Social support is important for managing stressor, but more than 50% parents loss it in case of disability. [17] There can be several reasons for that, mainly people feel that disability is associated with mothers' weakness and bad practice. As woman is considered second gender in Indian society, so reaction and stigma from society is more towards mothers. Therefore mothers face loss of support from spouse, family, in-law, relatives, friends, neighbour, community and society because of attached myths and social stigma with intellectual disability. Mothers face multiple stressors like extra time to child; need to perform other family duties, loss of social support, social stigma, social exclusion etc. which leads them to several psycho-social problems. [9,18] Parents of children with intellectual disability are facing more psychological problems compare to parents of typical child. [5,19] Parents of children with intellectual disability scored high in depression and anxiety disorder compare to parents of children with typical development [11] and mothers scored higher in anxiety and depression compared to fathers. [7,20,21]

As mentioned mothers are responsible for child care, same way fathers are responsible for outer affairs like financial arrangement and others resources. Child with ID need extra care, resources, special school and medical & therapeutically treatments, which comes under the responsibility of father. May be that's why fathers reported high financial difficulties compare to mothers of child with intellectual disability. They face financial difficulties in Visits to doctors, transportation, medical investigation, aids, appliances, visits to traditional healers, special school etc for their child treatment and learning. Study shown parents seek multiple treatment services for their child. [8] Mothers also reported financial difficulty but it was less compare to fathers, which show gender differences in division of

labour. Fathers face more burden and mothers face more stress. [22]

Mothers have to take care of child in all conditions, so whenever mothers go somewhere they spouse to carry their child with them and in case of ID it is necessary because of their special need. Mothers reported high embarrassment because of having child with intellectual disability, they feel embarrass to face family, relatives, neighbourhood, community etc. and they restrict their movement. They face double embarrassment, because of attached social stigma & cultural beliefs, another if they are in some social function or in social gathering still they need to mat with their child needs which limits their participation. Because of embarrassment, social stigma, work burden, restricted social movement which affect their relationship with spouse, in-law, family, relatives, friends, neighbour etc. [23] this study also depicts mothers relation are affected more compare to fathers. In case of parents of children with intellectual disability, quality of life is compromised. [6]

Siblings were affected by getting less time from parents, studies getting affected, having added responsibilities, recreation needs getting compromise, being teased by community, feeling isolated, worrying about future etc because of having a brother or sister with special need. Parents occupy with meeting needs of their special child, which leads them to compromise with needs of other children. Even siblings face increased responsibility and restricted house environment, which leads them to several difficulties' and learning. Literature also shown siblings of special child have both advantages and disadvantages. [24]

After being compromised with several issues, and because of social & psychological breakdown parents get negative thoughts like killing child, attempting suicide, restricting family size, separating child from family etc. Present study shown 2.8% mothers and 3.5 parents reported getting negative thoughts, which show females develop resilience being in

difficult environment. But literature shown mothers are more prone with negative thoughts and stress [14] which is no in present study. Differences in results might be because of cultural differences or due to study design Feeling of guilty because of having a abnormal child, makes them to get such negative thoughts because of increased psychological pressure. Parents feeling of guilty lead them to depression and anxiety. [11] In case of girl child ID parents also take decision of removal of reproductive organs. [3]

The negative impacts are one side of the story; mothers are more affected from negative affects of having child with ID, affects are associated with several social, cultural and physical environment. But they equally blessed with some positive impacts like more patience, more tolerance, more empathy, more sensitivity, more support and better relationship because of caring a special child. [25,26] That is one way of looking problem that parents of special child face lot of difficulty and they are negatively affected, but outcome also can be positive impacts. Study result shows mothers reported high positive impacts on them compare to fathers. Mothers care and supervise child for each and every work, they spend more time with child, face more difficulties that also makes to learn patience, tolerance, empathy, sensitivity, supportiveness, maintaining good relation. That shows more we face difficulties, more we learns, but not every time. The resilience of parents changes their difficult situation into positive results and sometime keeps away from psychosocial problems.

CONCLUSION

Broad literature and present study result shows that parents of children with ID, face several problems physical, social, financial and psychological. They face excessive work burden, social exclusion, social stigma, financial problem, lack of personal care, relationship breakdown, loss of social support, psychological problems etc. due to extra care and social pressure.

They visit several health professionals for treatment of their children, but there is no system to reduce their pressure and problems. At the end they are blessed with several positive affects to, which is predominant in mothers. So while making any intervention to disability management, we must take care of these facts. Appropriate professional intervention is needed.

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