



PSYCHOLOGICAL WELL BEING OF PARENTS IN RELATION TO EARLY INTERVENTION OF THEIR INTELLECTUALLY DISABLED CHILDREN

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ABSTRACT

Parents of intellectually disabled children face various levels of stress which increases with the increase in child-related demands associated with day to day things as well as long term goals which affect parental well-being globally. Early intervention turned out to be extremely effective in improving psychological health of parents as they feel that the child is now being taken care of by the experts. The aim of the present study was to determine the impact of early intervention of intellectually disabled children on the psychological well-being of their parents. Study also explored the difference between mothers and fathers separately on the same. The study was conducted on 60 parents by using purposive sampling technique from required population from different centers of Dehradun, Haridwar, and Rishikesh districts of Uttarakhand State, India. Pre-Post Quasi experimental design was used for the study. Paired 't' test and independent 't' test were used for exploring the results. Results revealed that early intervention of intellectually disabled children impact positively on the parental psychological well-being. Mothers showed very poor psychological well-being than that of fathers in pre test and did improved high level psychological well-being on the post test as compared to fathers counterparts.

Key Words: Psychological well-being, Parents, Disabled children, Intervention.

INTRODUCTION

Parents of disabled children get severely affected and become exhausted with time by facing challenges of raising a child with special needs and by taking care of the child's extra demands. This is due to the hardship that they experience while rearing a disabled child and also due to the social stigma associated with disability in Indian context. It also depends on the parents' perception of the challenges on having a special need child in their lives.

Continuous difficult routine and emergence of day to day challenges eventually affects the psychological well-being of the parents to a great extent. While facing the challenges of having a disabled child such as the daily care of the child, challenging behaviour issues, feeding difficulties, academics lagging, so on and so forth, they also have impact on themselves such as social withdrawal, isolation, losing a job or

compromising for a job not otherwise desired, financial difficulties, lack of self care and sense of humour, poor health, loss of self esteem and self confidence, diminished positive attitude towards life. Thus, the effect on parental psychological well-being is also indirect besides being direct.

Having a child with disability in the family also raises issues like embarrassment on the part of parents and other family members. This leads to hiding the child from society and depriving him/her from social exposure and all round development. Moreover, conflict between parents emerges from number of factors related to child's disability such as over or under protection, less time and care for each other, roles and responsibilities, excessive demands from the child, other psychological factors, etc.

Evidences are available from years which show significant impact of child's disability on parental psychological well being. The birth and demands associated with rearing a child with disability have always affected parental well being. Parental care for a child with a developmental disability is an enormous responsibility, one that can far exceed that of typical parental care. There is an increased demand on the care givers of children with developmental disability (McKinney, B., & Peterson, R. A., 1987).

For all parents there occur a period of adjustment, who expects a healthy and normal baby but have to accept the fact that their baby has a disability. Some parents find it easier to reconstruct their hopes for their child and their future than others. While most parents adapt well to the situation of caring for a child with a disability, some do not (Raina, P., O'Donnell M., Schweltnus H., Rosenbaum P., King G., Brehaut J., Russell D., Swinton M., King S., Wong M., Walter, S.D., & Wood, E. 2004).

Apart from having impact on parents, when mothers and fathers are compared, mothers have relatively poor psychological health than that of fathers. There are numerous reasons noticed and reported since long for this difference. Mother, especially in Indian context is expected to be the main care giver engaged full time with the disabled child at home whereas fathers are considered to earn livelihood for the family while being out for most of the time during the day. It is also expected that mothers can impart good care to the child with lots of endurance and are well versed with child rearing practices.

Fathers also have greater opportunities for distraction from challenges of child care due to their full time occupation outside the home letting them to be free from challenging responsibilities of the disabled child. However, there are evidences of reverse situation for fathers in few cases.

Mothers usually face greater challenges due to socio-cultural factors also. They are mostly blamed for the disability of their child, causing even more psychological distress. Some are aware of the facts that disability of the child is not their fault, sin or passed on by them biologically to the child but there are many who accept such blames and live with this guilt throughout their lives.

Intellectual disability is a condition of arrested or incomplete development of the mind and is especially characterized by impairment of skills manifested during the development period which contributes to the overall level of intelligence, i.e., cognitive, language, motor and social abilities (ICD-10, 2007). As clarified even more elaborately by AAIDD, Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers everyday social and practical skills. This disability originates before the age of 18 (David, T., and Derrer, 2013).

Early intervention refers to 'catching problems early', sometimes this refers to prevention, sometimes to early remediation, and sometimes the term is used to focus on early intervention in early childhood (Rogers, P., et. al., 2004). It is a system of coordinated services that promotes the child's growth and development and supports families during the critical early years (Paediatric & Child Health Division, 2013). It aims to stop those problems from becoming entrenched and thus to prevent children and young people from experiencing unnecessarily enduring or serious symptoms. Typically it achieves this by promoting the strengths of children and families and enhancing their 'protective factors', and in some cases by providing them with long term support (HARV, 2014).

Early intervention outcomes of interest go beyond the child's cognitive functioning to include child developmental gains as well as parent/family benefits in improved well being, teaching and parenting, and health care (Ramey, C.T., et. al., 2002).

Early intervention turned out to be extremely effective in improving psychological health of parents as they feel that the child is now being taken care of by the experts. Childhood intervention process, childhood intervention programs, family-centered early intervention practices, perceived program control appraisals, all these have direct or indirect positive effects on parents (Dunst, C. J., et. al., 2007).

Parents who participate in the intervention programme show better adaptation as they hold more positive perception and attitudes, are more confident, show lower level of emotional distress, anxiety and depression and perceive more emotional support from the spouse (Pelchat, D., et.al., 1999).

In the early intervention programmes it is expected that the parents also get the satisfaction of the progress seen in their children as a consequence of their improved psychological well being and somehow their compromises with life reduces. Thus, in order to see the significance of the early intervention programmes for children on the parental psychological well being, the present study was conducted. It was also expected that the findings of this study will help design the early intervention programmes widely to make it family focused and not just child focused.

METHODOLOGY

Aims

The aim of the present study was to fulfill the gap by means of two queries:

1. Does the early intervention of intellectually disabled children impact on the psychological well being of the parents?
2. Is there a difference of psychological well being between mothers and fathers due to early intervention of their intellectually disabled children?

Hypotheses

- (i) Early intervention of intellectually disabled children will affect positively on the psychological well being of their parents.
- (ii) Mother and father will differ significantly in the psychological well being due to early intervention of their intellectually disabled children.

Sample

The sample structure consisted of sixty parents (60 mothers and 60 fathers) of mild to moderate intellectually disabled children (IDC) in the age group of 2.5 to 6 years. Middle economic class and up to 8th standard educated parents were included in the sample. Study was done only on urban population by using purposive sampling technique. The study was based on pre and post Quasi-experimental design. The duration between pre and post test was six months. High scores indicate poor psychological well-being whereas low scores states better psychological well-being of parents of intellectually disabled children.

Data Collection

The sample was selected from different early intervention centers in two adjoining districts of Uttarakhand state, namely Dehradun and Haridwar. These are Karuna Vihar, Early Intervention Centre, Dehradun, Karuna Vihar, Child Development Centre, Dehradun, Arjita Home, Centre for differently able kids, Dehradun, Anugrah Child Development Centre, Dehradun, Abhiprerna Foundation, Ranipur, Haridwar, DPC, Kankhal, Haridwar and Jyoti Special School, Rishikesh, Dehradun.

Procedure

The overall data collection had two main parts. The *first part* was to assess the child's intellectual disability and to identify the category in which he/she falls. Sample was selected by first screening out children between the ages of 2.5 to 06 years those who fell in the category of Mild to Moderate intellectual disability. The criteria of Intellectual disability was followed as defined in the International Classification of Mental and Behavioural Disorders-10 (ICD-10). Parents of Intellectually disabled children with additional disability were not included in the sample. The *second part* aimed at exploring the psychological well-being of the parents of children identified as mild to moderate intellectual disability. The data from parents was further done in two parts, the pre-testing and the post-testing of psychological well-being. Data from mothers and fathers were obtained separately.

Measures

Early Intervention Technique: The early intervention services were provided to the children through activity-based play method by a team of experts that included physiotherapist, occupational therapist, special educator, communication specialist and psychologist, for 4 days a week on an average for approximately 2.5 to 3 hours every day. Mainly the mothers accompanied their children for the early intervention and fathers visited twice a week on an average for parents' empowerment sessions or discussions about child's progress. The parents were provided hands on training by the team of experts so as to enable them to feel empowered.

Vineland Social Maturity Scale (Indian adaptation by Rev. Fr. Dr. A. J. Malin and Enlarged edition by Dr. J. Bharath Raj): VSMS was used as a screening tool for sample selection. VSMS measures the development in terms of Social Quotient (S.Q.). The use of this scale at various places so far has confirmed its usefulness with the intellectually disabled children. It provides a definite outline of detailed performances in respect to which children show a progressive capacity. The items of the scale are arranged in order of normal average life age progression and in order of increasing average difficulty, and represent progressive maturation in self-help, self-direction, locomotion, occupation, communication and social relations. They have also been separated in year groups.

National Institute for the Mentally Handicapped - Disability Impact Scale (NIMH-DIS) [Hindi adaptation]: The scale was administered for assessing the psychological well-being of parents. Keeping the need of the study in view, this scale was adapted in Hindi. NIMH-DIS has been developed by Peshawaria R., Menon D.K., Bailey D., and Skinner D. (2002) for mentally handicapped to identify and assess (i) The nature and degree of impact on the parents (both positive and negative) because of having a child with Intellectual disability, the impact on the family members and the relationships within the family, and the impact with regard to relationships outside the family. (ii) Identify thrust areas for family intervention programmes. (iii) Objectively evaluate family intervention programmes. The impact has been studied in eleven areas: - Physical Care, Health, Career, Support, Financial, Social, Embarrassment/Ridicule, Relationships, Sibling effect, and specific thoughts. The item shows better psychological well being on low scores.

Statistical Treatment

Keeping in view the nature of data, Independent samples t-test and Paired samples t-test was applied. Apart from the above, Descriptive statistics- mean and standard deviation has also been worked out. All the calculations have been done using IBM SPSS Statistics Version 20.

RESULTS AND INTERPRETATION

Table 1-Pre-test and post-test scores on areas and on total psychological well-being of parents of intellectually disabled children (M, SDs and paired t-tests).

Areas of PWB	Pre-scores(N=60)		Post-scores (N=60)		t-value
	Mean	SD	Mean	SD	
Physical Care	14.90	4.48	11.30	3.51	8.73**
Health	9.23	4.91	7.75	4.16	5.14**
Career	5.62	5.27	5.08	4.29	2.30*
Support	8.40	5.22	3.90	3.15	9.10**
Financial	14.83	3.24	11.72	3.44	10.56**
Social	10.10	2.68	8.02	2.82	7.56**
Embarrassment/Ridicule	11.12	2.75	5.47	3.23	15.01**
Relationships	10.45	5.35	5.62	3.94	8.83**
Sibling effect	8.57	4.24	4.22	3.20	10.46**
Specific thoughts	4.45	2.34	2.73	1.96	4.38**
Total	97.82	29.14	65.90	21.65	12.11**

** p< .01 * p< .05

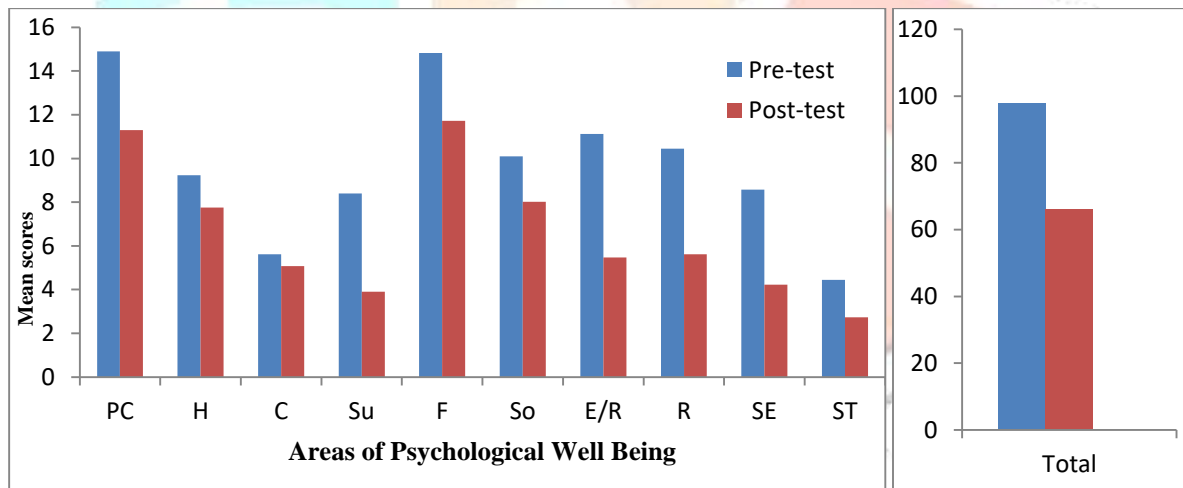


Figure 1- Comparison between Pre-test and Post-test scores on Psychological well-being of Parents.

Table-1 depicted that the parents showed significant difference between pre-test and post-test score on all aforementioned areas of psychological well being including the total. It is very obvious that early intervention of children has brought a remarkable improvement in psychological well being of their parents in positive direction.

Table 2 -Pre-test scores on areas and on total psychological well being of mothers and fathers of intellectually disabled children. (M, SDs, & t-tests).

Areas of PWB	Mother (N=60)		Father (N=60)		t-value
	Mean	SD	Mean	SD	
Physical Care	8.38	2.56	6.52	2.46	4.07**
Health	5.05	2.86	4.18	2.30	1.83
Career	2.90	2.82	2.72	2.50	.38
Support	5.53	3.53	2.92	2.51	4.67**
Financial	8.23	1.72	6.60	2.08	4.69**
Social	6.28	1.29	3.82	2.00	8.02**
Embarrassment/Ridicule	7.62	1.34	3.67	2.24	11.73**
Relationships	6.18	3.51	4.27	2.67	3.37**
Sibling effect	5.57	2.73	3.00	2.39	5.47**
Specific thoughts	2.63	1.58	1.82	1.10	3.28**
Total	58.23	19.42	38.55	15.03	6.21**

** p< .01.

As evident in table 2, a highly significant difference was found in the scores for mothers and fathers in pre-test in all the areas of psychological well being including total, except for the health and the career areas. Results also showed very poor psychological well being of mothers than that of fathers on the above significant areas.

Table 3 - Post-test scores on areas and on total psychological well-being of mothers and fathers of intellectually disabled children - (M, SDs and t-tests).

Areas of PWB	Mother (N=60)		Father (N=60)		t-values
	Mean	SD	Mean	SD	
Physical Care	5.98	2.45	5.32	2.23	1.56
Health	4.07	2.58	3.68	2.06	.90
Career	2.63	2.39	2.45	2.15	.44
Support	2.27	2.31	1.63	1.94	1.63
Financial	6.13	2.01	5.58	2.37	1.37
Social	4.67	1.65	3.35	2.16	3.75 **
Embarrassment/Ridicule	3.45	2.34	2.02	2.03	3.59**
Relationships	2.93	2.50	2.68	2.20	.58
Sibling effect	2.15	1.95	2.22	1.86	.19
Specific thoughts	1.38	1.20	1.58	1.36	.86
Total	34.80	15.61	29.05	12.59	2.22*

** p< .01, * p< .05

Table 3 states a significant difference between the scores of mothers and fathers on the areas of social and embarrassment/ridicule of psychological well being and in the total. Remaining all other areas were found not significant. However, mean values of other areas exhibited that improvement of mothers' well being in non-significant areas is less than the fathers.

Table 4 Pre-test and post-test scores on psychological wellbeing of Mothers of intellectually disabled children - (M, SDs & paired t-tests).

PWB areas	Pre-scores (N=60)		Post-scores (N=60)		t-values
	Mean	SD	Mean	SD	
Physical Care	8.38	2.57	5.98	2.45	7.65**
Health	5.05	2.86	4.07	2.58	4.47**
Career	2.90	2.82	2.63	2.39	1.69 *
Support	5.53	3.53	2.27	2.31	8.68**
Financial	8.23	1.72	6.13	2.01	9.33**
Social	6.28	1.29	4.67	1.65	7.29**
Embarrassment/Ridicule	7.62	1.34	3.45	2.34	14.97**
Relationships	6.18	3.51	2.93	2.49	8.85**
Sibling effect	5.57	2.73	2.15	1.95	10.53**
Specific thoughts	2.63	1.58	1.23	1.12	5.46**
Total	58.35	18.84	35.53	14.91	11.51**

** p< .01, * p< .05

As displayed in table 4, mothers showed significant differences between pre-test and post-test scores on all the areas of psychological well being including overall. This depicted that early intervention of intellectually disabled children impacts significantly at high level on the psychological well being of their mothers.

Table 5 Pre-test and post-test scores on psychological wellbeing of fathers - (M, SDs & paired t-tests).

PWB areas	Pre-scores (N=60)		Post-scores (N=60)		t-value
	Mean	SD	Mean	SD	
Phy. Care	6.52	2.46	5.32	2.23	5.48**
Health	4.18	2.30	3.68	2.06	3.15**
Career	2.72	2.50	2.45	2.15	1.96*
Support	2.87	2.58	1.63	1.94	5.86**
Financial	6.60	2.08	5.58	2.37	5.59**
Social	3.82	2.01	3.35	2.16	2.88**
Embarrassment/Ridicule	3.67	2.24	2.02	2.03	6.59**
Relationships	4.27	2.67	2.68	2.19	5.33**
Sibling effect	3.00	2.39	2.07	1.92	4.95**
Specific thoughts	1.82	1.10	1.58	1.36	.99**
Total	39.47	14.66	30.37	12.50	6.95**

** p< .01, * p< .05

Table 5 depicted significant differences between pre and post test scores of fathers of intellectually disabled children on all the areas of psychological well being including total. It is evident that early intervention impacts hugely on the psychological well being of fathers of intellectually disabled children.

DISCUSSION OF THE RESULTS

The results seemed to be reflecting improved Psychological well being of the parents of intellectually disabled children to a great extent. They have started feeling better by taking care of the day to day physical care needs of their disabled child, managing their own physical and mental health, getting positive towards their career and progress, improving their terms with family, friend and relatives and getting their support. They have also started feeling relaxed on financial front by managing better or earning more, involving in social activities, not getting embarrassed and affected by ridicule, devoting more time and efforts and managing better for siblings of their disabled child, overcoming from negative thoughts such as suicide, abandoning or killing the child and not having any more children.

Hence, the present research proves that early intervention makes a difference in how parents feel and empower themselves. It is also indicated in the study conducted by Crnic, K.A. (2017), a family-focused developmental systems approach, strategic parent skill training and mindfulness interventions needs emphasis. Similarly, based on their study, Islam, M.Z., Shanaz, R., & Farjana, S. (2013) have recommended special measures like early diagnosis, prompt treatment and counseling for mental and physical stress of the parents along with provision of need based rehabilitation services for the mentally retarded children at different levels to reduce the stress burden of their parents

On referring the results mentioned in the tables 2, it is obvious that before applying early intervention on the children, the mothers and fathers had visible difference in their overall psychological well being except health and career.

Although mothers on health area have showed high mean value or poor health than fathers, this may be attributed to different reasons such as lack of good care of health, overburden and work-life balance etc. which are the factors that affect physical and mental health of mothers more than the fathers of disabled children.

The results seemed to be reflecting better psychological health of fathers as compared to the mothers in both pre-test and also in post-test (table 2&3). The reason could be related to role specialization where mothers are more likely to be engaged in children (Haetley et al., 2014; Eagle and Wool, 2016), or may be other factors such as income and employment, as most fathers get chance to move out of homes for the sake of earning livelihood for the family, which in turn free them from facing the day to day challenges of raising a disabled child that are stronger predictors of well-being in fathers, which has also been found in research with fathers in the general population (Cooklin et al., 2015). Similar results were seen in the study conducted by Azeem, M.W., et al. (2013), according to them mother showed more anxiety and depression than fathers of intellectually disabled children.

The psychological well-being between mothers and fathers in pre-test as well as post-test showed improvement but mothers have improved much more than fathers as an impact of early intervention of their intellectually disabled children. In almost all the areas, the difference between the two groups diminished in terms of their psychological well-being. This shows that, though both the groups improved in their psychological well being but mothers have made a bigger jump, thus reducing the difference in the level of psychological well-being. In other words it can be said that although fathers showed better psychological well-being in pre-test scores, it is evident that mothers are more influenced in the positive direction by early intervention of their intellectually disabled children than fathers.

Unlike other areas, however, in the social, embarrassment/ridicule areas and the overall psychological well being, the difference remained significant between mothers and fathers even after providing early intervention to their children. The reason could be that mothers are still not getting satisfactory opportunities to involve in social activities and that they still feel more embarrassed about their disabled children. They are more concerned about the child's condition and try to hold themselves back from reaching out for social activities like entertaining occasions, opportunities to learn socially, family functions, etc. and try to hide the child from their social circle. Here, a big connection is seen between these two areas of psychological well-being. It's so relevant that embarrassment and fear of ridicule can also be a major factor for a mother to restrict herself from social activities. She may be facing negative comments or blames from family, relatives, friends, community, etc. which may push her even more to withdraw herself from social engagements.

CONCLUSION

As per aim of the study the following conclusions are drawn from the study:

1. The difference in the psychological well-being of parents improved significantly as a result of early intervention of their intellectually disabled children.
2. Mothers and fathers differed significantly in the areas as well as overall psychological well-being except the areas of health and career at the time of pre-test.
3. Mothers showed poor psychological well-being in pre-test than that of fathers.

4. Mothers & fathers both showed significant difference on social and embarrassment/ridicule areas.
5. Drastic improvement is seen between pre and post-test of mothers and fathers in all areas and in total well-being in terms of early intervention of their intellectually disabled children. Although mothers showed high positive impact of early intervention given to their children as compared to fathers.

LIMITATION AND SUGGESTIONS

1. There are number of things that could not be considered in the present research study due to various reasons, such as uncontrollable factors, time constraints and unavailability of desired resources. The time gap of six months between pre-test and post-test was less and the sample size was small which may have affected the results.

2. Three phases repeated measures pre-tests and post-tests research design and a bigger sample size is suggested for future similar research in order to get more reliable and valid results. Since the sample was restricted to two cities of one state only, a wider area, i.e. more cities and states should be chosen for better representation of sample.

3. Lack of uniformity of early intervention programmes at different centers leads to a suggestion for a uniformed structure of early intervention across different centers based on the effective theory behind it.

4. The design of the present research is Quasi experimental which has its own limitations. Hence, similar study with a control group is recommended.

5. Early intervention is an indirect strategy for parents because it is basically for children, which is expected to influence parents indirectly. Not only early intervention but other strategies, specially designed for the parents, should also be studied to see their impact on psychological well being. Similar studies including other disabilities also need to be conducted. Different disabilities can also be compared.

6. Separate studies for only mothers and only fathers can be conducted. Parents and caregivers should be fully included in the early intervention programmes in a structured way.

IMPLICATIONS

The highly significant impact of early intervention technique on the psychological well-being of parents of intellectually disabled children proves that there is a need to apply this technique consistently to elicit positive results in terms of parental psychological well-being. The findings indicated towards improvement needed in the early intervention programmes itself. A consistent structure of early intervention programmes will help catering to the psychological needs of parents. Areas of psychological well being in which highly significant progress occurred, indicates that early intervention services should be offered to the parents as soon as possible in a family-centered approach.

The early intervention programmes should be implemented with the help of better awareness of it for parents, special schools, early intervention centres and professionals responsible to provide early intervention services to the intellectually disabled children. There is also a need to generalize the impact on other disabilities as well.

This study also provide guidelines and ideas to the policy makers who can design the early intervention programmes more constructively and make it a mandatory strategy of any project finalized to function for the children identified with some or the other kind of disability. They can also address specific areas of psychological well being as studied in the present study.

Moreover, curriculum for training of teachers and special educators along with other professionals engaged in early intervention programmes can be formed in such way that it includes a holistic content for child development as well as parents' empowerment, support building and better physical and mental health.

Besides all the above implications, the funding agency must also provide adequate funds to implement early intervention services holistically while including parents, siblings, extended family members as well as the paid care givers.

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