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Research Paper

Is parental training effective in improving the quality of life of person with intellectual disability: An experimental research?

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ABSTRACT

Intellectual Disabled (ID) person has a right to live and received recognition and importance. There is a strong need to strengthen the social, emotional, physical and personal support systems among the families of these ID people and the society at large. The purpose of the study was to assess the effectiveness of parents training program in quality of life of children with ID on its dimension Health and Wellness (HW) and Rehabilitation and Education (RE). Binet-Kamat Test of Intelligence and Quality of Life Scale for Persons with Disabilities were applied. Analysis of covariance (ANCOVA) was applied on the pre test scores and post test scores obtained by the participants in the experimental and control group before and after the Parent Training Programme. It has found that parent training programme of individual with intellectual disability is effective and important interventional approach. That provides parents knowledge, guidance and understanding about their children and ways how to respond them in a positive, nurturing and proactive manner.

Keywords: *Intellectual Disabled, Parent Training, Quality of Life, Rehabilitation*

Parents with intellectual disability (ID) face many challenges that may affect their ability to parent effectively, and such shortages are often associated with various poor child outcomes. Children with intellectual disabilities are common and are increasing in number as more children survive globally. Intellectual disabilities, characterized by limitations in intellectual functioning as well as adaptive behaviors, are very common in children worldwide, with rates likely to increase as more children survive due to improved medical care.[1] Intellectual disable person has a right to live and received recognition and importance. However, it creates additional need for parents. There is a strong need to strengthen the social, emotional, physical and personal support systems among the families of these intellectual disabled children and the society at large. Intellectual Disability (ID) bring untold amount of misery, suffering and emotional distress to the parents of these unfortunate children. However, there is a well- known saying that the home is the first school for children and the mother is the first teacher. This is especially true in the case of children with ID. Family members giving care to the child with special needs may experience particular caregiver strain due to unusual demands including disrupted family

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and social relationships, exhaustion, guilt, and parenting distress. If the parents take responsibility to improve the quality of life or conditions of their children, they can turn the life of these children in better way even their given state of health. Provided, they are well informed with their own roles, responsibilities, Govt. schemes and benefits, coping strategies, behavior modification techniques, myth and misconceptions regarding the issues related to mental retardation.

Parents of children with intellectual disabilities have facing many challenges in their life. They often reported to have physical and psychological distress related to caring for their children, thus affecting their quality of life and increasing family burden. Earlier studies have shown that parents of children with disabilities feel the sense of failure, helplessness and guilt. [2] Mothers of children with ID displayed lower physical health, impairment in social relationships, in their psychological state and poorer perception of the environment. [3] Kumar,P et al (2019) emphasized that quality of life negatively related with economic family burden, family functioning, family relations, interpersonal relations of parents, other family burden. [4] It has also found that both parents perceive an equal level of psychosocial well- being on family burden and quality of life.[5] Parents of intellectual disability child have been perceived poor psychosocial well beings especially on area of quality of life and family burden domain. Negative correlations have been found between Quality of life, Family burden and IQ functioning. [6] Some studies have been conducted in Low and Middle Income Countries such as Kenya, Kuwait, Qatar and India which similarly report rates of 47–50% prevalence of psychological disorders amongst these parents. [7.]. Parenting such children may lead to difficulties with family functioning, parenting stress, and different parenting style compared to parenting normally developing children. [8]

McGaw *et al.* (2002) conducted a study to see the positive results of 'group intervention' to reduce emotional problems of parents of mentally retarded children. It has found that immediate and long-term benefits of group interactive process have beneficial effect to reduce parental stress. [9] A variety of parent training programmes have been developed to address such problems in children with developmental disabilities, Evidence for the effectiveness of group-based, video-modeling – assisted parent training for children with behavior problems, but without developmental disabilities is particularly compelling. [10]

Parent training programmes may be most valuable in assisting parents who are at risk of harming or damaging their child's healthy development (Keller & Mc Dade, 2000). Coren et al,(2018) has mentioned about randomised controlled trials (RCTs) of parent training programmes to improve parenting skills in parents with intellectual disability.[11].Hodes et al (2017) has discussed about adapted a video-feedback intervention to improve parent–child interactions and promote sensitive discipline by filming parent–child interactions then reviewing them with the parent and therapist to reinforce positive behavior. [12]

Quality of Life (QOL) is a complex concept, as there is no consensual definition of it and it can mean different things to different people.[13] QOL has been categorized into six domain (Quality of Home and Community Living, Health and Wellness-(HW), Rehabilitation and Education (RE), Employment-Income and Maintenance (EIM), Social- Recreational - Cultural (SRC), Personal- (P)) by Mishra, A [14], which was specially developed to measure the QOL of children with intellectual disability. Hence, the present study was an attempt to study the following objective and hypothesis: **Objectives:(i)**To study the difference between the experimental group and control group in the Quality of Life of Children with ID on its

dimension, Health and Wellness (HW) in terms of its four domains support, access, participation and satisfaction, after the Parent Training Programme (PTP).(ii)To study the difference between the experimental group and control group on the Quality of Life of Children with ID on its dimension Rehabilitation and Education(RE) in terms of its four domains support, access, participation and satisfaction, after the Parent Training Programme (PTP).

Hypothesis

(i) There would be significant difference between experimental group and control group after the Parent Training Programme (PTP) on Quality of Life of Children with Mental retardation on its dimensions Health and Wellness (HW) in terms of its four domains, support, access, participation and satisfaction. **(ii)**There would be significant difference between experimental group and control group after the Parent Training Programme (PTP) on Quality of Life Children with Mental Retardation on its dimensions Rehabilitation and Education (RE) in terms of its four domains, support, access, participation and satisfaction.

METHODOLOGY

Design

Pre Test - Post Test Treatment Designs was used to study the effect of Parent Training Programme on the quality of life of the parents having Children with ID. Place and duration of the study: The study was conducted between the periods of May 2013- July 2014 at three district of Haryana Rohtak, Jhajjer and Sonipat.

Participants

A group 240 sample was recruited in the present study, in which 120 persons with mild ID and 120 parents (both mother and father) with ID. Further 60 parents each in the experimental and control group were grouped.

Design to study the Effect of Parent Training Programme on the Quality of life Home

Table-1

	Pre-Test	**Post- Test**
Experimental Group	60 Parents (Both Father &Mother)	60 Parents (Both father & mother)
Control Group	60 Parents (Both Father &Mother)	60 Parents (Both father & Mother)

Tools Used

The Following standardized tools were applied in the present study to take the observation of the participants of both experimental and control group. **Binet-Kamat Test of Intelligence** (Indian Adaptation by, Kamat, (1934, 1957 & 1967) was used to assess the Intelligence Quotient (IQ) of the mentally retarded children to identify their level of retardation.[15]. **Quality of Life Scale for Persons with Disabilities (**Mishra, 2001) was used to measure the Quality of Home & Community Living (QHCL) dimension of the children with mental retardation.

Procedure

The study was divided into two phases In the First phase of the study: Permission from the different authorities of special school in Haryana was obtained. After that, tentative time schedule was developed in consultation with the authorities of the special schools in

Haryana and data was collected from the respondent who came to special school for consultation. They were briefed about the study tools. They were also informed about anonymity and confidentiality of the whole process of data collection. The Binet- Kamat Test of Intelligence was administered on 200 individuals with ID between the age group of 15-25 years. Out of 200 individuals with ID 120, 60 each in experimental and control group were selected randomly. The selected sample of 120 children (Experimental & Control Group) having mental retardation were administered the "Quality of life Scale for Persons with Disabilities," individually to explore the quality of life of these children. In the Second phase of the Study: Parent Training Programme was conducted for the experimental group in regular interval (quarterly) for two days (each day for 06 hours) throughout one year for the parents. They were exposed parent training programme through different modes i.e. by lectures method, providing written materials, audio-video presentation, individual and group counseling, role plays and Group discussion etc. In the parent training programme, many topics related to mental retardation and its issues were taken which are as follows: (a) Stress Management/Coping Strategies (b)Mental Retardation (Issues and Management) (c). Misconceptions about Mental Retardation. (d). Behaviour Modification (e)Training to Children with Mental Retardation(f)Child Abuse, (g) Role of Families and Parents. (h)Govt. Schemes and Benefits. (i) Points to be remember. After the one year of training, all the subjects i.e. 60 parents (Both father &mother) of experimental and 60 parents (both father & mother) of control Group were re-assessed to assess the impact of parent training programme on the Quality of Life Scale for the Children with Mental Retardation. Analysis of covariance (ANCOVA) was applied on the pre test scores and post test scores obtained by the participants in the experimental and control group.

RESULTS

Table-2

The F Value Table Showing the Difference between the Scores Quality of Health and Wellness Dimension of Quality of Life of the individual with ID in the Experimental and Control Group in the Pre Test.

Source	Sum of Squares	df	Means square	F value
GROUPS (Pre Test scores)	.026	1	.026	.010
Error	298.032	118	2.526	
Total	44506.063	120		

The **Table-2.** showed F value .010 which is not significant at .05 level of significance. Means there were no significant difference between experimental and control group on their pre test scores. It has indicated that no significant difference between experimental and control group on their pre test scores i.e., the independent variables and covariate that is outcome are not different across the group and satisfied the assumption to apply Analysis of Covariance.

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Table-3

The F Value Table showing the Scores of Quality of Health and Wellness dimension of Quality of Life of the individual with ID in the Experimental and Control Group to test the Homogeneity of Regression/

Source	Sum of Squares	Df	Means square	F value
GROUPS* (Pre Test scores)	5.706	1	5.706	2.201
Error	300.809	116	2.593	
Total	50114.125	120		

Table-3 showed the F value 2.20 which is not significant at.05 level of significance. That means no difference on the between subject effects on group time pretest So it's clear the assumption of homogeneity of regression to qualify for Analysis of covariance to test the significant difference between experiential and control group on the dependent variable (i.e., post test scores Health and Wellness dimension of the quality of life of the individual with ID with covariate independent variable i.e., pre- test scores of Health and Wellness dimension).

Table-4

The F Value Table Showing the Difference between Experimental and Control Group on the Health and Wellness Dimension of the Quality of Life of the individual with ID in the post Test.

Source	Sum of Squares	df	Means square	F value
GROUPS (Post Test scores)	82.781	1	82.781	31.598
Error	306.515	117	2.620	
Total	50114.125	120		

Analysis of covariance was applied to test the difference between the experimental group and control group on the dependent variable i.e., post test scores of the Health and Wellness dimension of Quality of life of the individual with ID. The F value came out to be 31.59** which is significant at .01 level of significance (**Table-4**) and the mean values of post test scores of experimental groups (21.15) and the control group (19.50) revealing the significant improvement on the Health and Wellness dimension of Quality of Life of the children with mental retardation in the experimental group than the control group.

Table-5

The F Value Table Showing the Difference between the Scores Quality of Rehabilitation and Education Dimension of Quality of Life of the individual with ID individual with ID in the Experimental and Control Group in the Pre Test.

Source	Sum of Squares	df	Means square	F value
GROUPS (Pre Test scores)	.408	1	.408	.125
Error	386.990	118	3.280	
Total	45764.250	120		

The table 5 showed F value .125 which is not significant at .05 level of significance. No significant difference has found between experimental and control group on their pre test scores (i.e., the independent variables and covariate that is outcome are not different across the group and satisfied the assumption to apply Analysis of Covariance).

Table-6

The F Value Table showing the Scores of Quality of Rehabilitation and Education Dimension of Quality of Life of the individual with ID in the Experimental and Control Group to test the Homogeneity of Regression.

Source	Sum of Squares	df	Means square	F value
GROUPS* (Pre Test scores)	168.297	1	168.297	1.713
Error	11493.433	117	98.234	
Total	1381324.000	120		

To test the assumption of homogeneity of regression, the result in the Table **Table-6** showed the F value 1.71 which is not significant at.05 level of significance. It means no difference on the between subject effects on group time pretest. Thus, satisfied the assumption of homogeneity of regression to qualify for Analysis of Covariance to test the significant difference between experiential and control group on the dependent variable (i.e., post test scores of Rehabilitation and Education dimension of the quality of life of the children with mental retardation with covariate independent variable i.e., pre test scores of Rehabilitation and Education dimension).

Table -7

F Value Table Showing the Difference between Experimental and Control Group on the Rehabilitation and Education Dimension of the Quality of Life of the individual with ID in the post Test.

Source	Sum of Squares	df	Means square	F value
GROUPS (Post Test scores)	117.471	1	117.471	55.222
Error	248.888	117	2.127	
Total	51515.500	120		

Finding of the table highlighted that significant difference between the experimental group and control group on the dependent variable (i.e., post test scores of the Rehabilitation and Education dimension of quality of life of the individual with ID). The F value came out to be 55.22** which is significant at .01 level of significance. The mean values of post test scores of experimental groups (21.63) and the control group (19.57) revealing the significant improvement on the Rehabilitation and Education dimension of quality of life of the individual with ID in the experimental group than the control group.

DISCUSSION

The present study was designed to see the effect of Parent Training Programme on the two dimensions of quality of life (one is Health and Wellness and another Rehabilitation and Education) of their children with mental retardation. Regarding effect of Parent Training Programme on the Quality of Life of individual with ID: The F value in the table-4 is 31.59** which is significant at .01 level of significance and indicating significant difference in the post test scores between experimental and control group on the Health and Wellness dimension of the quality of life of the children with mental retardation after the parent training programme. The mean values of post test scores of experimental groups and the control group are 21.15 and 19.50 respectively higher in case of experimental group than the control group, revealing significant improvement in the health and Wellness dimension of these children with mental retardation in the experimental group than the control group.

Hence, the hypothesis no. 1, that is, "There would be significant difference between experimental group and control group after the Parent Training Programme (PTP) on Quality of Life, on its dimension Health and Wellness (HW) in terms of its four domain, support, access, participation and satisfaction, is accepted and the results do find support from the earlier studies**.**

Ghasemi et al., (2010) studied the effectiveness of coping therapy on the enhancement of general health of mothers with genetic and non-genetic individual with ID " The result found the effectiveness of this therapy to enhance the general health of all the mothers, besides, reduction in their depressive and physical tiredness symptoms and improved their sleeps and social functions. [16] Drossman et al (2000) probed the effect of family training on the feelings of sadness, tiredness, guilt, gray and psychological pressure of parents who have individual with ID. At the end of this training program, the parents had a more feeling of success and reported less problems and better abilities for making decisions. [17] Anthony et al (2007) [18] surveyed the trace of a group intervention program on stress reduction of parents having mentally retarded children and the enhancement of these children general health. They found that these parents were increasingly vulnerable to stress and other problems related to mental health and this stress negatively affect the mentally retarded children, too. Anthony et al (2007) [18] in an investigation asserted that training stress management techniques to parents of mentally retarded children resulted in reduction of social avoidance style, negative attributions to the child, and improvement of affective relations and enhancement of parents' mental health as well as their children. Trostre (2001) showed that teaching strategies for effective coping with mental pressures to parents of individual with ID had positive effects on reduction of their stresses and mental health improvement of both the parents and children with mental retardation. [19]

Another objective of the study was to assess the difference between the experimental group and control group on the Quality of Life of Children with ID on its dimension Rehabilitation and Education (RE) in terms of its four domains support, access, participation and satisfaction, after the Parent Training Programme. In the Table-7 the F value came out to be 55.22** which is significant at .01 level of significance and the mean values of post test scores of experimental group and the control group came out to be 21.63 and 19.57 respectively. The higher mean value of the experimental group in their post test scores indicating the significant improvement on the Rehabilitation and Education dimension of quality of life of the individual with ID in the experimental group than the control group. Hence, the hypothesis no. 2 that is, "There would be significant difference between experimental group and control group after the Parent Training Programme (PTP) on Quality of Life of Children with Mental Retardation on its dimension Rehabilitation and Education (RE) in terms of its four domains, support, access, participation and satisfaction, is accepted. The earlier studies do support the result of the present study.

According to Aron and Loprest (2012) education is important for the all children but even more important for children with disabilities or special needs as it can mean the difference between a socially fulfilling, intellectually stimulating and economically productive life and a future with few of these quality. [20] Education and rehabilitation also have potential to affect the health of the children with mental retardation by strengthening their abilities to advocate for themselves, manage chronic health conditions and navigates complex medical, insurance and social service system and in turn improve their quality of life during childhood and later in life. Further, many disabilities moreover are actually manifestation of

physical or mental limitations within specific social or environmental contacts and of the behavioural or performance expectations of socially defined roles which are the challenges and that can only be answered through rehabilitation and education of these children along with the education and awareness of their parents. According to Krishnamurthy (2011) Rehabilitation and Community Based Rehabilitation is a strategy for equalizing opportunities, poverty reduction and social inclusions of persons with disabilities which strengthen physical and psychological well-being of the persons with children with mental retardation against the demanding conditions of the society in the area of health, social, educational and more over empowerment and livelihood. [21]

Lastly it can be said that parents training of individual with ID are effective to enhance the quality of life of individual with ID. At present its demand of our society to achieve the goal of positive mental health and enhance the quality of life of individual with ID as well as their parents. So, it's great responsibilities of professionals/policy makers/researchers to accept this challenge and provide care to this vulnerable as well as needy person. The professionals (mainly special educators/mental health professionals) can help the parents to cope with the crisis by examining the resources of the Family, including role structure, emotional and financial stability and can help them to deal effectively with the situation. [22]

Implications of the Present Study

(a) implementation of individualized programme system (b)Planned with an annual schedule for parent involvement in different activities, where attendance should be carefully monitored (c)Encouraging parent's visit to rehabilitation centers regularly and their participation in different activities with the children of the centers. (d)Strengthening periodic professional – parent consultation programme, parent to parent intervention programme and the training of the parents through parent workshop/training programme at least twice a year.

Limitations of the Present Study

There are few limitations of this study that may be addressed in future (a) the present research is delimited to children having mild and moderate level of mental retardation. (b)The presented study is delimited to only two dimensions of quality of life.

CONCLUSION

Parent training programme of individual with intellectual disability is effective and important interventional approach. Recent findings also support the present study that there was a significant difference between the experimental and control groups, and the quality-of-life perceptions of the parents with ID that participated in the training improved [23]. This improvement was observed in the subdomains of parenting and emotional well-being dimensions in the Beach Center Family Quality of Life Scale. That provides parents knowledge, guidance and understanding about their children and ways how to respond them in a positive, nurturing and proactive manner. This has also helped the parents to increase their confidence and reduce family burden, so that they can perform their job successfully. Helping parents raise their mentally retarded children more effectively can produce positive outcome for the child, reduce the parental stress and promote his/her mental health as well as welfare of our society. May & Harris K (2020) emphasized about better quality research and longer term follow-up studies are needed, with increased inclusion of fathers. Lack of availability of these types of targeted parenting programmes in the community may be a

substantial barrier and may vary by geographic location. Specific training of professionals in how best to help parents with intellectual disability and associated service development, in an evolving disability funding environment, may create a new pathway to support these parents in need.[24]

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Conflict of Interest
The author declared no conflict of interest.

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