ORIGINAL RESEARCH PAPER

Effectiveness of Psychoeducation on Psychological Wellbeing and Self-Determination in Key Caregivers of Children with Intellectual Disability

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ABSTRACT

INTRODUCTION : For the parents to have a child with intellectual disability becomes the most traumatic experience of life which makes them unenthusiastic to accept the fact. Studies havemostly tended to focus on parental adjustment to their child's disabilityand its correlates. There is littleresearch examining interventions that aim to improveparents' and children's relationship or quality of life. This study aimed to see the effectiveness of psychoeducation in increasing the level of psychological well-being and self-determination of the caregivers of children with intellectual disability (ID). Methodology: A total of 20 caregivers of children with intellectual disability were purposively selected from Central Institute of Psychiatry and Deepshika Institute of Child Development and Mental Health, Ranchi. They were assessed with General Health Questionnaire (GHQ-28), Ryff's Psychological wellbeing scale, Family Interview for Stress and Coping in Mental Retardation (FISC-MR), Social Problem Solving Inventory (SPSI-R) and Self-determination scales before giving the psychoeducation. The psychoeducational module was developed specially for the caregivers based on National Institute of Mental Health manual for Psychologists and Teachers, Counsellors manual for family intervention in mental retardation & Problem Solving therapy manual. This module was applied on them individually for the period of four weeks. The measures mentioned earlier were used again to assess the post treatment levels on the selected key caregivers. Results: Study identified significant increase in the caregiver's psychological well-being and self-determination levels after eight sessions of psychoeducation. Conclusions: Results suggested that psycho-educational intervention is effective in increasing knowledge regarding the condition and in meeting the needs of the care givers. There are very few culturally sensitive parent intervention practices directed to the key caregivers of children with intellectual disability and that these practices should be enhanced.

Keywords: Intellectual disability, psychological wellbeing, self-determination, psychoeducation

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INTRODUCTION

Intelligence is an aggregate or global capacity of the individual to act purposefully, to think rationally and to deal effectively with his environment.[1] Cognitive or intellectual ability is used to learn, understand, imagine, remember, think, adapt and modify our surroundings. Specifying this fact, it is no wonder that a diminished intellectual capability puts significant limitations on the person's functioning.[2]

The parents of children with ID becomesubdued to accept the fact and continue to feel dejected as their expectations are not fulfilled. Their pain becomes more severe whenever they see other children and their progress in various facets of life. In the initial stages, they may go through the highly distressing and confusing emotions of shock, disbelief, disappointment, anger, guilt, misery, helplessness, and worries about the future of the child. Later the nature of stress can span over several aspects of family life such as daily care demands, emotional distress such as maternal depression, interpersonal difficulties like parental discord, financial problems and adverse social consequences like isolation and stigmatization.[3]

Numerous studies, [4-5] tend to highlight the negative aspects of having a child with disability. These negative factors include affecting the family's self-esteem burdening the family's emotional resources and coping strategies, interrupting the normal routine of the family and depriving personal growth opportunities. These negative impacts may lead parents to adopt maladaptive coping skills including feelings of guilt, pessimism, hostility, aggression and avoidance which affect their entire wellbeing. [6-7]Self-determination and control over one's own life is critical for all individuals, including individuals with developmental disabilities.[8]

There is a growing body of literature showing the effectiveness of parenting interventions for families headed by parents of children with ID.[9] It has been demonstrated that parents of children with intellectual disabilities can learn to provide positive and stimulating parent–child interactions, improve basic child-caring and problem-solving skills, develop shopping and food preparation skills, improve home cleanliness and safety and identify appropriate approaches to child behaviour management. Education and training programs strive to help caregivers by educating them about resources and by teaching specific problem solving and coping techniques thus to improve the psychological wellbeing.[10] Problem-solving and behaviour management interventions demonstrate the greatest effectiveness.[11] Psycho-educational interventions teaching either mood management skills or problem-solving skills were effective in reducing depression, reducing burden, and increasing coping.[12]

Published research on interventions for parents with IDs has generally described programmes that have been implemented in controlled settings by the programme developers operating in clinic- like conditions and using manualized and highly structured delivery. It has been observed that attention has been less given to the use of evidence-based programmes by professionals and only few examples of successful dissemination of such interventions are being come to light [13]. There is thus a need for 'translational' research that seeks to identify the conditions under which interventions are effective for parents in the wider community when implemented by practitioners. If the biopsychosocial model is applied in the context of intellectual disability, it needs to be understood that professionals cannot do much to change the biological condition, which interacts with the psychological and social resources of the parents. However, the latter two attributes (psychological and social variables) are malleable and hence can be the targeted for the intervention. Thus, parents' knowledge and involvement are crucial in dealing with their children with ID. Therefore we undertook the study with a tailored module to analyse the efficacy of psychoeducation in psychological wellbeing and self-determination of key caregivers of children with intellectual disability.

METHODOLOGY

This study was a pre-post study conducted at Central Institute of Psychiatry and in Deepshika Institute, Ranchi. Total of 20 samples were selected through purposive sampling technique. The samples of the study were one key caregiver of each 20 children with intellectual disability. Fifteen key caregivers of children with intellectual disability were selected from the Erna Hoch Centre for Child and Adolescent Psychiatry of

Central Institute of Psychiatry and remaining 5 key Caregivers were taken from the Deepshika Institute for Child Development and Mental Health, Ranchi. The children were clinically assessed using clinical data sheet and were diagnosed in accordance with the International Classification of Disease- 10th Revision-Diagnostic Criteria for Research, (ICD-10- DCR). Socio demographic and clinical data was collected and level of disability by Assessment of Disability in Persons with Mental Retardation (ADPMR). Intelligence level of the child was assessed by the clinical psychologist of the institute and the score was recorded. Caregivers were assessed with General Health Questionnaire-28 (GHQ-28),[14] Ryff's Psychological wellbeing 42 item scale, Family Interview for Stress and Coping in Mental Retardation (FISC-MR),[3] Social Problem Solving Inventory-Revised scale, [15] and Self-determination scale by Sheldon & Deci. After this initial part, psychoeducation was given to the caregiver for a period of four weeks, a total of eight sessions which was done twice a week. Feedback was taken after every session. The module for psychoeducation was prepared with the objectives of providing the general information about intellectual disability, removing myths and family maladaptation and to teach planful problem solving ability to the selected key caregivers. This psychoeducational module was developed under the mentioned sources: a) 'Behavioural approach in teaching mentally retarded children, a manual for teachers',[16] b) 'Mental Retardation', A manual for Psychologists',[17] c) Counsellors manual for family intervention in mental retardationand d) 'Problem-Solving Therapy, a treatment manual.[18] This psychoeducational module was developed specifically for this study and extra attention was given to make this intervention suitable for these people. This module was designed with tentatively eighth sessions and each session was planned to last 45 min to 1 hr. The details of the session format is given.

Sessions	Purpose & Content
1st session	**Objective:** Building Therapeutic alliance ▪ Briefing about the study o About the sessions and content. ▪ SWOT Analysis o Strength & weaknesses (Internal), Opportunities and Threats (External) was recorded.
2nd session	**Objective:** Assessment of Knowledge regarding Intellectual disability ▪ Applied- Check & Know – 25 Questions; o Adopted from "Behavioural Approach in Teaching Mentally Retarded Children; A Manual for Teachers" ▪ Myths and facts related to intellectual disability- From their Knowledge
3rd session	**Objective:** Sharing of finding & Educating - Myths and Facts associated with Intellectual Disability. ▪ Result of 25 questions was revealed. ▪ Discussed Myths & Facts with explanations. ▪ Shared other common misconceptions about intellectual disability- Adopted from Counsellors Manual for Family Intervention in Mental Retardation by Dr. Satish Chandra Girimaji
4th session	**Objective:** Psychoeducation about Intellectual disability ▪ Concept and Definition ▪ Prevalence ▪ Causes and Prevention of Intellectual Disability. Adopted from o 'Mental Retardation', A manual for Psychologists o Clinical Practice Guidelines for the Diagno sis and management of Children with Mental Retardation by Dr. Satish Chandra Girimaji
5th session	**Objective:** Post assessment of myths & facts ▪ Assessment of Check & Know – 25 Questions ▪ Other common misconceptions about intellectual disability Adopted from o "Behavioural Approach in Teaching Mentally Retarded Children; A Manual for Teachers" o Counsellors Manual For Family Intervention In Mental Retardation by Dr. Satish Chandra Girimaji
6th session	**Objective:** Handling Family maladaptation ▪ Managing Expressed emotions ▪ Handling adverse family consequences Altered social life, Stigma/Embarrassment. Adopted from o Counsellors Manual For Family Intervention in Mental Retardation by Dr. Satish Chandra Girimaji
7th& 8 th sessions	**Objective:** Brief planful problem solving training ▪ Teaching individual 4 planful problem solving skills ▪ Use of problem solving worksheet.

The key Caregivers of these children were re-assessed with GHQ-28, Psychological Wellbeing Scale, FISC-MR, SPSI-R and self-determination scales after the 8 sessions of psychoeducation.

RESULTS

The collected data were analysed by the Statistical Package for Social Sciences (SPSS) version 22. Distribution of variables was represented in terms of frequency and percentage.

Pairedsample 't' test was used to compare the pre - post parametric data.

Regarding the socio demographic and clinical data, majority of the family (75%) belongs to lower socio economic status and majority (85%) of the mothers were caring their children with intellectual disability. The average age of children with intellectual disability was 10.05 ± 4.57 years, and average ages of father and mother were 37.85 ± 5.54 and 32.40 ± 5.41 years respectively. Average father's education was 11.10 ± 3.86 years and mothers were 10.30 ± 4.29 years. Average monthly income of them was rupees 15300.00 ± 10498.62.The average IQ level of the children assessed by the psychologist is 47.85 ± 13.35 and the mean percentage of disability was found to be 55.25 ± 15.76.

Table 1 shows the comparison of the scores of general health in the caregivers between baseline and after four weeks of the psychoeducation using paired t-test. From the table, it is evident that there is significant improvement in all the domains of GHQ-28. There is also a significant improvement in the total score ($p < 0.001$) of general health after four weeks of psychoeducation in comparison to the baseline scores.

Table 2 shows the comparison of the scores of psychological wellbeing in the caregivers between baseline and after four weeks of the psychoeducation using paired samples t-test. The analysis revealed that there is highly significant improvement in all the domains and in the total score of Ryff's Psychological wellbeing scale after four weeks of psychoeducation in comparison to the baseline scores.

Table 3 shows the comparison of the scores of family's Stress and Coping in the caregivers between baseline and after four weeks of the psychoeducation using paired t-test. Higher the score in section I indicate higher the stress perceived and higher the score in section II indicates lower the use of coping strategies. The analysis revealed that there is significant difference in all the domains of section I and section II of FISC-MR. There is also a significant improvement in the total score of both the sections of family's Stress and Coping in mental retardation ($p<0.001$) after four weeks of psychoeducation in comparison to the baseline scores.

Table 1 : Comparison of the scores of general health in the caregivers

	Variables	Pre $\bar{x}$ ± SD	Post $\bar{x}$ ± SD	t (df=19)	Sig (p)
GHQ-28	Somatic Symptoms	4.55 ± 2.41	0.40 ± 0.75	8.69	.000***
	Anxiety Symptoms	3.60 ± 2.52	0.20 ± 0.41	6.18	.000***
	Social Dysfunction	7.90 ± 1.97	2.20 ± 1.32	14.82	.000***
	Severe Depression	1.90 ± 1.44	0.10 ± 0.30	5.91	.000***
	Total score	17.95± 6.59	2.90 ± 2.12	12.278	.000***

Table 2 : Comparison of the scores of psychological wellbeing in the caregivers

	Variables	Pre $\bar{X}$ ± SD	Post $\bar{X}$ ± SD	t (df=19)	Sig (p)
Ryff's Psychological wellbeing	Autonomy	19.35 ± 4.55	30.15 ± 2.87	12.87	.000***
	Environmental mastery	22.75 ± 2.53	29.95 ± 2.30	10.25	.000***
	Personal growth	23.50 ± 3.48	31.20 ± 3.31	8.41	.000***
	Positive relations	26.35 ± 2.77	31.35 ± 1.95	9.05	.000***
	Purpose in life	24.95 ± 2.68	31.00 ± 2.20	8.71	.000***
	Self-acceptance	22.30 ± 3.04	29.60 ± 2.43	9.76	.000***
	Total	139.20 ±14.22	183.25 ± 11.29	15.80	.000***

Table 3 : Comparison of the scores of Family's Stress and Coping

Variables		Pre $\bar{x}$ ± SD	Post $\bar{x}$ ± SD	t (df=19)	Sig (p)
Section-I	Daily care stress	10.45 ± 2.83	6.10 ± 1.94	13.65	.000***
	Emotional stress	6.15 ± 2.39	2.50 ± 1.43	12.10	.000***
	Social stress	4.85 ± 1.30	1.95 ± 0.88	16.45	.000***
	Financial stress	2.30 ± 0.65	1.90 ± 0.55	3.55	.002**
Total		23.75 ± 5.89	12.45 ± 4.00	16.88	.000***
Section-II	General Awareness	6.35 ± .93	3.30 ± .73	22.55	.000***
	Attitudes & Expectations	7.45 ± 1.43	3.95 ± 1.09	18.92	.000***
	Rearing practices	4.80 ± 1.00	2.75 ± .71	13.35	.000***
	Social support	2.40 ±.59	1.70 ± .65	6.65	.000***
	Global family adaptation	2.50 ± .68	1.85 ± .58	5.94	.000***
Total		23.50 ± 3.87	13.55 ± 3.18	23.03	.000***

Table 4 : Comparison of the scores of social problem solving ability

	Variables	Pre $\bar{x}$ ± SD	Post $\bar{x}$ ± SD	t (df=19)	Sig (p)
Social problem solving Inventory	Avoidance style	10.05 ± 2.52	4.30 ± 1.55	11.33	.000***
	Negative problem orientation	15.15 ± 2.49	6.60 ± 1.69	18.30	.000***
	Rational problem solving	10.70 ± 2.93	21.80 ± 1.70	18.17	.000***
	Impulsiveness/ Carelessness style	12.75 ± 2.61	4.35 ± 1.08	15.28	.000***
	Positive problem orientation	5.60 ± 1.50	9.35 ±1.49	10.80	.000***
	Total	54.25 ± 4.33	46.40 ± 2.98	6.244	.000***

Table 4 shows the comparison of the scores of social problem solving ability in the caregivers between baseline and after four weeks of the psychoeducation using paired t-test. The analysis revealed that there is significant improvement in all the domains of avoidance style, negative problem orientation, rational problem solving, impulsiveness/carelessness style and positive problem orientation. There is also a significant improvement ($p<0.001$)in the total score of SPSI-R after four weeks of psychoeducation in comparison to the baseline scores.

Table 5 : Comparison of the scores of self-determination

	Variables	Pre $\bar{x}$ ± SD	Post $\bar{x}$ ± SD	t (df=19)	Sig (p)
SDS	Awareness of self	12.55 ± 2.74	18.80 ± 2.01	9.63	.000***
	Perceived choice	15.55 ± 2.68	12.95 ± 2.64	3.03	.007**
	Total	28.10 ± 3.29	31.75 ± 2.02	4.104	.001**

Table 5 shows the comparison of the scores of self-determination in the caregivers between baseline and after four weeks of the psychoeducation using paired t-test. The analysis revealed that there is highly significant improvement in the domains of awareness of self ($p<0.001$), perceived choice ($p<0.01$), and in the total score of self-determination ($p<0.01$), of the caregivers between baseline and after the psychoeducation.

DISCUSSION

The intervention was effective in alleviating a greater percentage of somatic symptoms, anxiety and insomnia, social dysfunction and depression of the caregivers. The results confirmed that most of the care givers had difficulties in managing their children and learned how to manage their children and felt less irritated which resulted in reducing their problems after the psycho education. There was lack of information and knowledge regarding the nature and causes of disability which lead them to be in the darkness of myths and facts. By providing information regarding the disability, its nature, causes, prevalence helped them to gain knowledge about their children's condition that in turn improved their well-being. Information about the available support and services helped them to reduce the suppressed senses of learned helplessness. It reduced the future-oriented anxiety, guilt and shame among family caregivers.

Several studies,[4,7,19] have demonstrated that mothers and fathers, of mentally handicapped children, experience more stress than the parents of healthy children, and experience higher levels of stress. By making the family realizing that the stress and negative feelings they have are more about the disability rather than about the child with diminished functioning, helped them to understand things better and to cope with the challenges they are facing. Accepting the fact and to take responsibility by not denying the condition of their children through the intervention reduced the stress perceived by the care giver. Dealing family maladaptation reduced the fear and actual instances of stigmatisation and thus increased coping strategies within them. Enhancing spiritual believes and helping them to identify adequate resources such as seeking support and services from family, friends, community and professionals helped them to handle adverse consequences and build on healthy social responses. The recent socio-cultural changes in India appear to have had an adverse influence of increasing the stress faced by the families in caring for individuals with mental retardation, and hence call for greater professional involvement and support. During the training, the caregivers were taught how to define a problem, identify the possible solutions, selecting the most realistic solution, and solution implementation which helped them to increase positive and planful problem orientation and to decrease negative problem orientation, impulsiveness and avoidant style of problem solving. By practising the problem solving worksheet might have helped the caregivers to analyse the pros and cons of alternatives of a problem and thus to reach the goal. Through psychoeducation the caregivers approached the problems in a reasoned, deliberate and systematic way rather than avoiding and confronting the painful reality.Several factors predicted higher levels of self-determination, including educational setting, the presence of challenging behaviours, and perceived disability severity. They concluded by offering recommendations for equipping parents to better support their children's self-determination development. Acquiring information about self-regulation skills and realising about their own capacities and opportunities helped the caregivers to act in a self-determined way. This might have helped the caregivers to develop a self-identity as a competent parent. The findings of the present study are consistent with both empirical and theoretical literature suggesting that providing parents of children with intellectual disabilities with skills mastery experiences in the context of caring for children with disabilities will enhance their psychological wellbeing.[20] Skills training for parents were effective and helped parents to develop healthier and more positive psychological well-being.[21] Teaching specific caregiver skills that are clearly operationalized, practiced, and used to resolve real-life problems have been found to produce significant changes in outcome measures directly related to those skills.[22] Results showed that there were differences in term of parental stress as well as psychological wellbeing before and after the parents of children with disabilities attended the interventional program.[23,24] Moreover, psychoeducation improved

parent optimism and sense of self-efficacy in addressing their child's adaptive behaviour needs.

LIMITATIONS

The sample size was small hence result cannot be generalized. There was no follow up assessments to assess the long term efficacy of psychoeducation. There was no control group, sampling was done in a purposive manner which if it had been randomized would have led to greater generalizability.

Implications & Future directions

The current study has several important implications for caregivers of adults with intellectual disabilities. The current results, in combination with previous literature, continue to illustrate that the caregivers of children with intellectual disability tend to experience stress and, as a result of psychoeducation given for four week they are more likely to experience lower levels of anxiety and overall distress. Changes in parental knowledge and their attitude towards their children's disability improved psychological wellbeing as a result of the intervention proved the efficacy of psychoeducation. These findings confirm that expanded implementation of psychoeducational interventions for caregivers of patients of children with ID can be beneficial for both caregivers and children, and since the care of the latter depends on the former, interventions enhance the quality of life of both. Parents with positive perceptions can help the other parents in the early stages of adjustment develop positive but realistic expectations. This results light-on to the future for good researches in the same area with large population.

Future studies should increase the sample size so that results could be better generalized. Randomized sampling should be used for better results. Gender differences in the parents can also be incorporated in the future studies Different types of intellectual disabilities should be studied separately. Effect of difference in parenting strategies and coping mechanisms used by the caregivers should be studied. Qualitative research would be appropriate to identify any additional factors that may interfere with parents' psychological well-being and general quality of life.

CONCLUSION

It can be concluded that by making the caregivers equipped with information for initial recognition and sustained awareness of the child's behaviour is critical for the effectiveness of intervention as they serve as a window for immediate and more effective treatment. Educational, informative and psychological counselling to the caregivers of mentally handicapped individuals will help them in adapting to their environment, in the best way. These trainings will aid them to understand their feelings and thoughts about themselves and their children, to accept their children with their abilities and disabilities and to re-determine their boundaries for the future in a more realistic way. At the end of this study, education offered to the caregivers of children with intellectual disability, was found to be effective in improving psychological wellbeing, social problem solving ability and self-determination. Based on the results and experiences obtained from the study, a planned education is recommended for the caregivers of all mentally handicapped individuals. The necessary steps for this purpose are; the provision of appropriate institutions to offer psychoeducation, as well as the formation of comforting counselling groups where the parents of a handicapped individuals meet other parents and express their feelings, meeting the supportive requirements with the aid of educational materials, encouraging the professionals to play a role in improving and applying educational program held with caregivers of handicapped individuals.

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