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Effect of brief psycho-education module on psychological wellbeing and family burden in caregivers of children with intellectual disability

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Abstract

Background: The birth of a child with intellectual disabilities can disrupt family expectations and impose significant burdens on caregivers, leading to poor psychological well-being. Psycho-education has emerged as a promising intervention to support caregivers in managing these challenges.

Objective: This study aimed to evaluate the impact of a brief psychoeducation module on the psychological well-being and family burden of caregivers of children with intellectual disabilities.

Methods: A pre-test, post-test design was employed with 20 caregivers recruited from the Ranchi Institute of Neuro-Psychiatry & Allied Sciences (RINPAS) in Kanke, Ranchi. Participants were randomly assigned to an experimental group receiving both treatment as usual and the psychoeducation module, or a control group receiving only treatment as usual. The intervention comprised 10 sessions conducted over 10 weeks for the experimental group.

Results: The study revealed no significant differences in the sociodemographic variables of caregivers and children between the experimental and control groups. However, the intervention had a positive impact on the psychological well-being of caregivers in the experimental group, particularly in areas such as autonomy, environmental mastery, positive relationships with others, and sense of purpose in life, compared to the control group. Although there were no significant differences in financial burden after psychoeducation, the experimental group demonstrated a significant reduction in disruptions to routine family activities, family leisure, and family interaction, accompanied by improvements in physical and mental health when compared to the control group.

Conclusion: The brief psychoeducation module demonstrated significant improvements in caregivers' psychological well-being and family dynamics, underscoring its efficacy in supporting families of children with intellectual disabilities.

Keywords: Intellectual disabilities, caregivers, psychological well-being, family burden, psychoeducation

Introduction

The birth of a new child in a family is typically a time of joy and anticipation, filled with dreams and aspirations for the future. However, when a child is born with intellectual disabilities, it can shatter these expectations and bring about profound emotional turmoil for the family. Intellectual disability, previously referred to as mental retardation (MR), is a condition characterized by significant limitations in intellectual functioning and adaptive behaviors, often presenting before the age of 18 (APA, 2000; Schalock, Luckasson, & Shogren, 2007) [2]. Globally, 52.9 million children under the age of 5 experience a developmental disability, such as sensory impairment, intellectual disability, and autism spectrum disorders. Of these, 95% live in low-and-middle-income countries (Salomone *et al.* 2019) [20]. In India, studies indicate a prevalence of intellectual disability of approximately 0.6% across various states (Murthy, 2017) [4], while recent meta-analysis estimates suggest a prevalence of around 2% (Russell *et al.*, 2022) [3].

The impact of intellectual disability extends beyond the individual affected to profoundly influence the family unit and caregivers. Baxter, Cummins, and Yiolitis (2000) [5] underscored that intellectual disability imposes greater burdens on families and caregivers compared to other forms of disability. Following the diagnosis of intellectual disability in their children, caregivers often experience emotional distress and diminished wellbeing (Panicker & Ramesh, 2019) [6], leading to psychological strain and increased familial burden (Ramasubramanian *et al.*, 2019) [7]. Moreover, societal stigma surrounding intellectual disability often leads families to withdraw from social interactions, exacerbating their sense

of isolation and exhaustion (Kaur & Arora, 2010) [8]. Psycho-education emerges as a promising intervention to address the multifaceted needs of caregivers and families. Bäumel *et al.* (2006) [9] define psycho-education as a systematic, didactic approach to provide patients and their families with information about the illness and its management, facilitating understanding and coping. Lukens and McFarlane (2006) [10] suggest that psycho-education interventions, coupled with health education and information dissemination, can empower caregivers and enhance their ability to navigate the challenges associated with intellectual disability.

Despite the potential benefits of psycho-education, there remains a dearth of research on its efficacy and implementation in India. The complex needs of families in a developing country necessitate tailored interventions to support caregivers of children with intellectual disabilities. Hence, this study aims to explore the efficacy of a psycho-education module on caregivers of children with intellectual disabilities, to develop effective support mechanisms and strategies to empower these families.

Aim

The study aims to evaluate the impact of a brief psychoeducation module on the psychological well-being and family burden of caregivers of children with intellectual disability.

Methodology

The study was conducted at the Ranchi Institute of Neuro-Psychiatry & Allied Sciences (RINPAS) in Kanke, Ranchi. A pre-test, post-test design was employed, with an experimental group receiving both treatment as usual and a psychoeducation module, and a control group receiving only treatment as usual. The intervention consisted of a total of 10 sessions conducted over 10 weeks for the experimental group. A total of 20 caregivers of children with intellectual disabilities were recruited for the study, with participants equally divided into the experimental and control groups. Purposive sampling techniques were utilized to select participants from RINPAS.

Inclusion criteria for the caregiver of children with Intellectual disability

- Caregivers of children, diagnosed with Intellectual disability (Mental retardation) as per ICD-10 DCR (Moderate and Severe level).
- The age range of the children 6-10years.
- Intellectual disability children of either sex.
- Caregivers actively involved and living in the same house for more than 2 years.
- The age range of caregivers between 25 to 40 years.
- Caregivers who give written informed consent.

Exclusion criteria for caregivers of children with Intellectual disability

- History of any major Physical or Psychiatric illness or other co-morbidity, Substance abuse/dependence.
- The caregiver who cares for children directly and living in the same house with other mental illnesses.

Tools

The RYFF scale of Psychological well-being-54 item (Carol Ryff, 1989, 1995): The Ryff Scale of Psychological

Well-being (RPWB) assesses psychological well-being across six dimensions: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance. It consists of 84 items, with 14 items per dimension, rated on a six-point scale. Higher scores indicate greater well-being. The scale demonstrates good reliability (Cronbach's alpha = 0.88) and validity, with aggregated subscale alphas of 0.72-0.88.

Family Burden Interview Schedule (FBIS) (Shaila Pai and R.L., Kapur, 1981): The Family Burden Interview Schedule (FBIS) is a semi-structured interview tool developed by Shaila Pai and R.L. Kapur in 1981. It comprises 24 items grouped into 6 areas, assessing various aspects of burden experienced by families of individuals with intellectual disabilities, including financial burden, disruption of routine family activities, and effects on physical and mental health. Each item is rated on a three-point scale, with satisfactory validity and reliability demonstrated in the Indian context. The Hindi translation of the schedule has been previously utilized in research (Kumar & Kumari, 2002) [21].

The module of brief Psychoeducation to the caregivers of children with Intellectual disability

The brief Psychoeducation module is tailored for caregivers of children with intellectual disabilities. Participants will engage in 10 sessions held at RINPAS, Kanke, each lasting 45 minutes to 1 hour. During the initial session, the focus is on program orientation and establishing a therapeutic relationship between the caregivers and the facilitators. Subsequent sessions delve into specific topics, beginning with an assessment of knowledge and dispelling myths surrounding intellectual disabilities. Awareness of the disorder is then addressed in the third session, followed by discussions on treatment availability in the fourth session. The fifth and sixth sessions explore the critical role of caregivers in the management of intellectual disabilities. In the seventh session, caregivers are informed about available schemes and provisions to support their caregiving responsibilities. The eighth session is dedicated to stress management techniques tailored to the unique challenges faced by caregivers. The ninth session focuses on problem-solving strategies to address common issues encountered in caregiving. Finally, the tenth session involves termination and feedback, allowing caregivers to reflect on their journey and provide input for future program improvements. Through this structured approach, caregivers are equipped with the knowledge, skills, and support necessary to navigate the complexities of caring for children with intellectual disabilities effectively.

Procedure

In this study, 20 participants were selected using purposive sampling, meeting the inclusion criteria outlined for the study. These participants were randomly divided into two groups: an experimental group and a control group, each comprising 10 participants. Written informed consent was obtained from all participants prior to their involvement in the study. At baseline, all participants were assessed using a sociodemographic datasheet, the RYFF Scale of Psychological Well-being, and the Family Burden Interview Schedule. The experimental group received 10 sessions of the brief psychoeducation module in addition to their usual

treatment, while the control group received only their usual treatment. Following the completion of the 10 sessions, the study sessions were concluded. Participants were reassessed using the same questionnaires

to evaluate any changes after the termination of the psychoeducation intervention.

Results

Table 1: Comparison of Socio demographic variable of caregivers between experiment group and control group

Variables		Samples (N=20)		X ² / Fisher Exact Test	P
		Experimental group N=10 (N %)	Control Group N=10 (N %)		
Religion	Hindu	8(80%)	9(90%)	2.62	.474
	Islam	0	1(10%)		
	Christian	0	0		
	Sarna	2(20%)	0		
Category	General	0	0	1.97	.628
	OBC	7(70%)	6(60%)		
	SC	0	2(20%)		
	ST	3(30%)	2(20%)		
Mothers' age at the marriage	≤18	0	0	.000	1.00
	19-22	6(60%)	6(60%)		
	23-30	4(40%)	4(40%)		
	Above 30	0	0		
Mothers' age during delivery	≤18	0	0	1.05	.714
	19-22	1(10%)	2(20%)		
	23-30	5(50%)	3(30%)		
	Above 30	4(40%)	5(50%)		
Marriage Type	Consanguineous	0	0	-	-
	Non- Consanguineous	10(100%)	10(100%)		
Type of delivery	Normal	4(40%)	4(40%)	.000	1.00
	caesarean	6(60%)	6(60%)		
Mother occupation	Housewife	10 (100%)	10 (100%)	-	-
	Daily wages/Working Professional	0	0		
Father occupation	Daily wages	1(10%)	4(40%)	3.54	.643
	Self employed	4(40%)	2		
	Private Job	3	3		
	Govt Job	1(10%)	1(10%)		
	Agriculture	1(10%)	0		
Family Monthly income	Below 10k	0	2(20%)	2.95	.573
	10001-20000	2(20%)	3(30%)		
	20001-30000	6(60%)	3(30%)		
	Above 30000	2(20%)	2(20%)		

Table 1 presents a comparison of the sociodemographic variables between caregivers of children with intellectual disabilities in both the experimental and control groups. Regarding religion, the majority of individuals in both groups identify as Hindu, with 80% in the experimental group and 90% in the control group. Islam is represented by 10% in the control group, while 20% of the experimental group follows the Sarna religion. None of the individuals fall under the General category, while the OBC (Other Backward Class) category is predominant in the experimental group (70%) compared to 60% in the control group. ST (Scheduled Tribe) individuals represent 30% of the experimental group and 20% of the control group. In terms of mothers' age at marriage, the most common age

range for marriage is 19-22 years in both groups (60% each). Most deliveries occur between the ages of 23-30 during delivery, with 50% in the experimental group and 30% in the control group. Marriages in both groups are non-consanguineous, and the distribution of normal versus cesarean deliveries is equal in both, with 40% each. All mothers in both groups are housewives. The father's occupation varies across groups, including daily wages, self-employed, private job, government job, and agriculture. Family monthly income mostly falls in the range of 20001-30000 in both groups. Statistics and corresponding p-values indicate that there are no significant differences observed between the experimental and control groups for each variable.

Table 2: Comparison of Socio demographic variable of children between experiment group and control group

Variables		Samples (N=20)		t (df=18)	p
		Experimental group (N=10) (Mean ± SD)	Control Group (N=10) (Mean ± SD)		
Age of the children		8.60±1.17	7.40±1.50	1.988	.308
		Experimental group N=10 (N %)	Control Group N=10 (N %)	X ² / Fisher Exact Test	p
Children gender	Male	7(70%)	7(70%)	.000	1.00
	Female	3(30%)	3(30%)		
Age of detection of disability	1-5	10 (100%)	10 (100%)	-	-
	5-10	0	0		
Schooling	Home based	10 (100%)	10 (100%)	-	-
	School/day care	0	0		
Disability severity	Moderate	5 (50%)	7(70%)	.833	.650
	Severe	5 (50%)	3(30%)		

Table 2 compares the sociodemographic variables of children in an experimental and a control group. The mean age of children in the experimental group is 8.60 years (SD ±1.17), while in the control group, it is 7.40 years (SD ±1.50). Both groups have an equal representation of males and females, with 7 males and 3 females each. All children were diagnosed with disabilities between ages 1 and 5 and

received home-based schooling exclusively. The experimental group has a slightly higher proportion of severe cases of disability. However, the Chi-square test shows no statistically significant differences between the two groups in terms of age, gender, age of disability detection, schooling, and disability severity.

Table 3: The Comparison of Psychological Wellbeing of Caregivers of children with Intellectual Disability between baseline and after psychoeducation

Domains of Psychological well being		Samples (N=20)				U	p
		Experimental group N=10		Control Group N=10 (M ±SD)			
		Mean Rank	Sum of the rank	Mean Rank	Sum of the rank		
Autonomy	Pre	9.35	93.50	11.65	116.50	38.50	0.37
	Post	14.80	148.0	6.20	62.0	7.0	0.001
Environmental Mastery	Pre	12.60	126.0	8.40	84.0	29.0	0.11
	Post	14.90	149.0	6.10	61.0	6.0	0.001
Personal Growth	Pre	10.95	109.50	10.05	100.50	45.50	0.73
	Post	14.20	142.00	6.80	68.0	13.0	0.005
Positive Relations With Others	Pre	11.95	119.50	9.05	90.50	35.50	0.27
	Post	15.50	155.0	5.50	55.0	0.00	0.000
Purpose in Life	Pre	10.35	103.50	10.65	106.50	48.50	0.90
	Post	15.50	155.0	5.50	55.0	0.00	0.000
Self-Acceptance	Pre	9.15	91.50	11.85	118.50	36.50	0.305
	Post	14.20	142.0	6.80	68.0	13.00	0.005

Table 3 compares two groups, an experimental group, and a control group, regarding various domains of psychological well-being before and after Psychoeducation. The analysis reveals that the intervention significantly improved autonomy, environmental mastery, positive relations with

others, and purpose in life in the experimental group compared to the control group. However, there were no significant differences in personal growth and self-acceptance between the groups after the intervention.

Table 4: The Comparison of Family burden of Caregivers of children with Intellectual Disability between baseline and after psychoeducation

Domains of Psychological well being		Samples (N=20)				U	p
		Experimental group N=10		Control Group N=10 (M ±SD)			
		Mean Rank	Sum of the rank	Mean Rank	Sum of the rank		
Financial Burden	Pre	8.70	87.0	12.30	123.00	32.00	0.164
	Post	8.35	83.50	12.65	126.50	28.50	0.093
Disruption of routine family activities	Pre	10.50	105.0	10.50	105.00	50.00	1.00
	Post	6.60	66.0	14.40	144.00	11.00	0.002
Disruption of Family leisure	Pre	11.10	111.0	9.90	99.00	44.00	0.64
	Post	6.10	61.00	14.90	149.00	6.00	0.000
Disruption of Family interaction	Pre	10.80	108.00	10.20	102.00	47.00	0.82
	Post	6.15	61.50	14.85	148.50	6.50	0.001
Effect on Physical Health of others	Pre	12.70	127.0	8.30	83.00	28.00	0.065
	Post	7.60	76.00	13.40	134.00	21.00	0.015
Effect on Mental Health of others	Pre	12.55	125.5	8.45	84.50	29.50	0.088
	Post	6.30	63.00	14.70	147.00	8.00	0.001

Table 4 compares the family burden of caregivers of children with intellectual disabilities before and after receiving psychoeducation, dividing participants into experimental and control groups. The analysis indicates several notable findings. While there were no significant differences in financial burden between the groups post-psychoeducation, the experimental group exhibited a significant reduction in disruption of routine family activities, family leisure, and family interaction compared to the control group. Additionally, the psychoeducation intervention led to a statistically significant improvement in the physical and mental health of others within the experimental group.

influenced by their sociodemographic characteristics. In our study, we compared the group of caregivers who received a brief psychoeducation module with those who did not, and we found several key findings. Firstly, Hinduism was the predominant religion in both groups, which is reflective of the regional demographics. The study done by Nagarkar *et al.* (2014) [11] found that 71.7% (43) of the 60 patients were also Hindu. There was a higher prevalence of OBC individuals in the experimental group, which suggests that there may be socioeconomic disparities that impact caregiving dynamics. Similarly, both groups had a notable proportion of caregivers from ST backgrounds, which indicates that there are unique sociocultural factors at play. Mothers' age at marriage and delivery were similar between groups, indicating consistency in marital and reproductive

Discussion: The experiences of caregivers are significantly

patterns. Both groups primarily practiced non-consanguineous marriages, and there was an equal distribution of delivery modes. Housewives were the primary caregivers, which aligns with traditional gender roles. Variations in fathers' occupations highlighted diverse socioeconomic backgrounds. Despite income variations, both groups fell within the middle-income bracket. Intellectual disability is more prevalent in families of low income status (Ten Hoope-Bender, 2014) ^[12]. There were no statistically significant differences in age and disability severity, indicating that the random assignment of children to groups effectively balanced sociodemographic factors. Both groups had an equal representation of males and females, with 7 males and 3 females each. The studies report that the prevalence of mental retardation is higher among males than females. A meta-analysis discovered that the ratio of females to males with intellectual disabilities among children and adolescents ranged from 0.4 to 1.0, indicating that for every ten males with the condition, there were four to ten females with ID (Patel *et al.*, 2013) ^[13]. Overall, the similarities in sociodemographics imply that differences in psychological well-being post-intervention were likely influenced by the psychoeducation module rather than underlying sociodemographic factors.

The results of the current study indicate that the psychoeducation intervention had a positive impact on certain aspects of the caregivers' psychological well-being, enabling them to handle their caregiving responsibilities more effectively and form more positive relationships. Psychoeducation leads to increased knowledge, coping skills, social support, empowerment, and better parent-child relationships. This reduces stress and increases resilience among caregivers, improving psychological well-being. This finding is consistent with previous research. Studies conducted by Krishnan *et al.* (2018) ^[15], Sin *et al.* (2017) ^[19], and Sawyer, Tao, and Bailey (2023) ^[14] have shown that psychoeducation is an effective way to improve the psychological well-being of caregivers. These studies have demonstrated significant improvements in mental health and a reduction in global morbidities, underlining the importance of psychoeducational programs in promoting and safeguarding the mental well-being of caregivers.

The results revealed no significant differences in financial burden between the experimental and control groups. However, the experimental group demonstrated significant improvements in other aspects, including disruption of routine family activities, family leisure, and family interaction, as well as improvement in physical and mental health within the experimental group. This suggests that psychoeducation may have equipped caregivers with effective coping strategies and resources to manage caregiving demands, leading to enhanced family functioning. These findings align with prior research by Iyidobi *et al.* (2022) ^[18], Ponce *et al.* (2011) ^[17], and Yu *et al.* (2023) ^[16], which concluded that participants who received psychoeducation experienced reduced caregiver burden and improvements in mental health and emotional well-being.

Conclusion

Psychoeducation interventions offer valuable support to caregivers of children with intellectual disabilities, leading to enhanced psychological well-being and reduced family burden. These results emphasize the significance of

incorporating psychoeducational programs into comprehensive support systems for caregivers, to manage the challenges that come with caregiving responsibilities.

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