

BRIEF REPORTS

Efficacy of Family Intervention in Acquired Head-Injury Cases in India

N. Krishna Reddy^{1*}, Mysore Narasimha Vranda²

1. Additional Professor, Department of Psychiatric Social Work, NIMHANS, Bangalore, India

2. Assistant Professor, Department of Psychiatric Social Work, NIMHANS, Bangalore, India

ABSTRACT

Purpose: *In India, there are few studies on interventions for families of persons with acquired or traumatic brain injuries. This study aimed to test the efficacy of the Family Intervention Package (FIP) with caregivers of persons with head injuries.*

Method: *The study was carried out at the Neuro-Surgery Department of the National Institute for Mental Health and Neuro Sciences (NIMHANS), Bangalore, India. Ninety persons with severe head injuries and their caregivers were included in the study using the socio-demographic schedule and family interaction pattern scale.*

Results: *The findings revealed that the Family Intervention Package (FIP) was effective in bringing about changes in the functioning of persons with head injuries, and interactions among their families in the experimental group, as compared to the control group.*

Conclusion: *The multi-disciplinary team dealing with persons with head injury need to recognise the importance of multi-component FIP for this group and their families. The current FIP should be made a part of treatment in clinical settings.*

Key words: *traumatic, acquired, head injuries, family intervention*

INTRODUCTION

Traumatic Brain Injury (TBI) is a silent epidemic of modern times and a serious health concern. National level data are not available for traumatic brain injuries in India. The only epidemiological study undertaken in Bangalore City has

*Corresponding Author: Dr. N. Krishna Reddy, Additional Professor, Department of Psychiatric Social Work, Dr M V Govindaswamy Centre, NIMHANS, Bangalore 560029, India. Email:dr.nkreddy@yahoo.com

revealed that the incidence, mortality and case fatality rates were 150/1,00,000, 20/1,00,000 and 10%, respectively (Gururaj, 1995, 2002). At the national level, nearly two million people sustain brain injuries, 0.2 million lose their lives and nearly a million need rehabilitation services every year. In the city of Bangalore, around 10,000 people sustain brain injuries every year, and there are more than 1,000 deaths. The majority of these individuals, who are young males, are often involved in road traffic accidents. The financial loss to the nation is estimated at about Rs.350 crores annually (Gururaj, 1995, 2002). Advances in neuroimaging and improved management have resulted in an increasing number of survivors who suffer from chronic problems, leading to an increased demand for rehabilitation services. Multicentric outcome studies have shown that 35% of persons with severe head injuries will die, 1-5% will remain vegetative and 5-18% will continue to have severe disabilities six months after TBI (Leishman, 1998; Sankla et al, 1998).

Head injury is generally conceptualised as a continuum that ranges from very mild, brief or no loss of consciousness, to extremely severe and prolonged coma. The severity of head injury and recovery of injured persons often depends on the nature of the injury. Significant neuro-psychological impact is common during the post-recovery stage among persons with TBI.

Behavioural problems associated with closed head injuries are common, and represent major obstacles to rehabilitation efforts designed to help affected persons resume productive domestic or community roles (Garoutte & Aird, 1984). During the acute recovery phase after trauma, moderately to severely injured persons may exhibit a range of behavioural disorders such as restlessness, agitation, combativeness, emotional lability, confusion, hallucinations and other disturbed perceptions, disorientation, depression, paranoid ideation, hypomania, and confabulation (Garoutte & Aird, 1984; Kwentus et al, 1985). These behavioural problems are more disturbing, burdensome, and unacceptable to family members than the physical stigma (Bond, 1984). Families that experience the greatest subjective burden typically cite behavioural problems, including quick temper, irritability, and apathy as most troublesome (Teasdale & Jennect, 1976).

When brain injury occurs, the injured people's families and significant others are affected. Complex and enduring problems and hardships that family caregivers face include social isolation, depression, anxiety, anger, blame, lack of knowledge about brain injury, and guilt (Garoutte & Aird, 1984; Lezak, 1988). Consequently, coping with a brain injury is complex, impacts many domains, and requires meaningful

timely information and intervention (Kwentus et al, 1985; Stoler & Hill, 1998).

Many researchers have documented disruptions in family functioning (Kreutzer et al, 1994) as manifested by less effective coping, problem-solving and communication (Anderson et al, 2002). The negative consequences for many severely injured survivors include confusion, inability to learn from experience, dependency, anxiety, and impaired social awareness (Prigatano & Schachter, 1991). In relation to these impairments, family members are often thrust into caregiving roles and experience significant strain. Since brain injuries affect a significant proportion of younger people, caregiving poses distinct challenges as survivors often require long-term care throughout their expected lifetimes (Flanagan, 1998). Disability due to head injury causes greater economic hardships, strains families and leads to disruption and also marital dissolution (Kreutzer et al, 1994).

Extensive literature on family needs indicates that family members rate the needs for information and emotional support very high (Sinnakaruppan & Williams, 2001; Leith et al, 2004). Early intervention and advocacy (Rotondi et al, 2004) and community reintegration (Cripe, 1987) are considered important. However, many important needs are identified as unmet (Leith et al, 2004).

For the family of a person living with a brain injury, the treatment and psychosocial rehabilitation process is a semi-rational sequence of demands, challenges, disappointments, and rewards. An important question to consider is: where, when, and how are families going to get the support, resources, knowledge, encouragement, role models and skills they need to negotiate the emotional and physical perils of changing healthcare and a demanding psychosocial rehabilitation process? As evidenced by literature, an individual's TBI often has a great impact on the family as a whole. TBI can affect the family's organisational structure, level of emotional distress, adjustment, financial stability, communication patterns, problem-solving skills, roles and responsibilities of each member, and the ability to balance the family's needs. While the importance of family and caregiver involvement in TBI rehabilitation has been acknowledged by researchers, in practice strategies that move beyond treating the individual have rarely been implemented. This has resulted in many rehabilitation programmes largely ignoring the importance of family relations, needs for support, and psycho education (Maitz & Sach, 1995; Gan et al, 2006). However, the importance of research and clinical intervention that includes the survivor and the family is

slowly being recognised, notably in the form of family support and the provision of psycho education about brain injury (Maitz & Sach, 1995).

Barriers to conducting family intervention studies do exist. Although many researchers agree that family members are adversely affected by brain injury and are likely to benefit from treatment (Gordon et al, 2006; Ragnarsson, 2006), few have developed evidence-based interventions for survivors and their families. One reason for the paucity of family intervention studies may be the intensity and rigour required to recruit families, conduct a prolonged intervention, and collect data.

There is limited literature on intervention studies in the Indian setting with regard to families of ABI or TBI. The aim of this study therefore, was to test the efficacy of the Family Intervention Package (FIP) with caregivers of persons with head injuries.

METHOD

Sample

The study was carried out at the National Institute of Mental Health and Neuro Sciences, Bangalore. NIMHANS is an institution recognised in India and South East Asia for its contributions to service, training and research in the area of Mental Health and Neuro Sciences, and also Traumatic Brain Injuries. With a multidisciplinary integrated approach, the institute's Neurosurgery Department provides care for persons with trauma on a 24-hour basis, including emergency services, outpatient clinics thrice a week, where nearly 150 follow-up cases are seen each time and a 123 bed inpatient unit, to accommodate persons with severe head injuries.

For the current study, 90 persons with severe head injury were selected. Inclusion criteria were persons above 18 years of age, who were in the Neurosurgery inpatient unit for treatment with no history of previous head injury. Exclusion criteria were persons with co-morbid psychiatric problems, intellectual or memory deficits including dementia. Those without focal deficits were also excluded. The subjects were assigned at random to the experimental group (EG) consisting of 50 persons with head injuries and their families, and the control group (CG) consisting of 40 persons and their families. The age of the subjects ranged from 18-58 years, with the majority of 44 % in EG and 35 % in CG belonging to the 18-27 year age

group. The experimental group (EG) and the control groups (CG) had 76% and 65 % males respectively. Hindus were 88% in EG and 93% in CG. 63 % in EG and 58 % in CG were married people. Majority (75%) of the persons with head injury in both the groups were literate and belonged to the lower income group. With regard to the cause of injury, 60% in the EG and 65% in CG had head injuries due to motor vehicle accidents; the rest in both the groups had head injuries caused by falling from stairs, from heights, on the play-field and industrial accidents. Family data were obtained from the people identified as providers of long-term care to the injured persons. The majority (76% and 65%) of the participating family members (or caregivers) in both EG and CG groups respectively, were males between 18-37 years of age. 90% and 87% of family caregivers in EG and CG respectively were employed.

Measures

Socio Demographic Data Sheet: The researchers prepared a socio-demographic data sheet to collect background information on the subjects and their family members.

Family Interaction Patterns Scale (FIPS) (Bhatti et al, 1986): The FIPS has 106 items, used to assess the interaction patterns of the family on six areas: leadership, communication, role, reinforcement, cohesiveness, and social support system. Total scores on the scale range from 106 to 424. Scores below 137 demonstrate healthy family functioning and scores above this show dysfunction in family functioning and interaction. The scale has sound validity and reliability (0.98) and is widely used with diverse groups in Indian settings.

Procedure

Screening of case files was done initially and family members were later contacted during their stay in the ward. At the initial intake session, the researcher provided information about the intervention programme, confirmed eligibility and interest in participation, identified the primary family members and obtained informed consent from all participants. After giving informed consent, the family members in both groups were asked to complete FIPS to assess the family functioning prior to the occurrence of head injury.

Family Intervention Programme

The Family Intervention Package (FIP) was envisaged as a means to improve the

family members' understanding about the impact of head injury on survivors and the recovery process, as well as to improve family interaction, problem-solving and coping skills, to help set realistic goals, and to strengthen social support through utilisation of community resources. The FIP was implemented over a period of 90-120 minutes. Each family attended 8 sessions where two topics were addressed. These are presented in Table 1. The sessions were organised logically for better therapeutic effect.

Apart from this, the family members also attended the group intervention programme in order to generate social support. The group sessions were conducted during the hospitalisation of the injured persons. On an average, every family member attended 5-6 sessions, each of which lasted from one to one-and-a-half hours. Each group consisted of 6-8 families per session, and about 4 sessions were held for each group. Around 6 group sessions were conducted in the in-patient ward. Services such as occupational rehabilitation, speech therapy, and orthopaedic consultations were provided for those who needed them, by liaising with other departments in the institute and related organisations. Financial assistance was also provided for 15 persons to obtain medicines and meet hospital expenses. At the time of discharge, contact details were collected from all the people in the experimental group. They were given dates for the follow-up visit, and the researcher's contact number in case of any emergency. They also had the option of letter-writing in case they were unable to return. The researcher made home visits to those who missed the follow-up session. Additional inputs, depending upon the nature of the problem reported by the family members, were given at the follow-up session. Activity Schedules were prepared, to give structure to the daily activity of the injured person. Those who developed post-traumatic stress disorder (PTSD), neurological problems, or speech problems were referred to the appropriate service departments. Visits were also made to the workplaces of those who were employed prior to the head injury, in order to facilitate their return to work. Employers were informed about the injured employee's condition and about the environmental modifications that would be required.

Table 1: Family Intervention Package

Session	Approach/Model	Content
Understanding the impact of Brain Injury	Educational	Normal brain functions; understand the typical consequences of brain injury (for injured person and family), recognise that brain injury affects the whole family.
Understanding the Recovery Process of the injured person	Educational	Nature and impact of head injury on person's functioning. Physical, cognitive, behavioural, psychological impact of head injury on person, recovery process, difference between emotional and physical recovery, understand the deficits, and appreciate the natural limits of rehabilitation, how to cope with loss and change, and family role in recovery and rehabilitation of the injured person.
Communication Skills	Practical/Educational and Discussion	How to communicate with injured person, different level of communication. How to identify the non-verbal cues of injured person.
Problem Solving and setting Realistic Goals	Practical/Educational and Discussion	Identify the problem issues; use the strategy–advantage-disadvantages approach to solve the problem effectively. Understand the family expectations of the injured person, know the dangers of unrealistic expectation and its impact on recovery, setting of realistic goals, steps to set up reasonable and achievable goals
Stress and Emotional Management	Supportive Educational Practical/Demonstration	Recognise the early signs of stress -'red flags', impact of stress, strategies for effective stress management and self-care. Impact of negative emotions on injured person and oneself; managing negative emotions especially anger, frustration, fear, sadness and anxiety.

Utilisation of Community Resources	Educational	Strengthen the social network of family, recognise and address gaps in the system of care, provide information on services available in the community for successful rehabilitation of the injured person.
Group Intervention	Supportive Educational	Help the family share their unrealistic fears and loss, build the confidence of the family members; provide sense of support through sharing.

RESULTS

a. Family Interaction Patterns

Table 2: Family Interaction Patterns

Sl. No	Variables	Pre-Treatment			Post-Treatment			6 Months Follow-up		
		EG	CG	't'	EG	CG	't'	EG	CG	't'
1	Reinforcement	15.0 (4.36)	14.5 (2.75)	0.69	21.3 (3.60)	23.8 (3.81)	2.92**	15.9 (2.69)	26.8 (4.77)	13.58***
2	Social Support System	16.1 (4.46)	15.3 (4.54)	0.77	19.3 (5.29)	19.9 (6.09)	0.28	15.8 (3.47)	21.2 (6.19)	5.23***
3	Role	37.7 (8.31)	36.4 (7.16)	0.77	53.4 (8.50)	50.3 (8.49)	1.73	39.7 (4.84)	52.72 (7.81)	9.94***
4	Communication	39.0 (10.12)	36.05 (7.53)	1.58	51.5 (8.66)	46.6 (9.32)	2.55***	38.8 (4.63)	48.5 (8.99)	6.59***
5	Cohesiveness	22.7 (7.57)	20.9 (5.39)	1.26	34.7 (6.21)	34.80 (6.28)	0.08	25.8 (3.59)	31.2 (7.19)	4.58***
6	Leadership	24.1 (6.57)	23.1 (5.72)	0.77	33.4 (7.80)	36.6 (7.25)	0.50	25.9 (4.46)	31.1 (7.69)	4.01***

* P<0.01; ** P<0.05; *** P<0.001

In the pre-treatment field, non-significant results were found between the experimental group and control group in all the sub-domains of the family interaction scale. In the post-treatment field, significant difference was found in the domain of reinforcement (P<0.00); communication (P<0.001) in the experimental group was comparable to the control group. In the area of follow-up after six months of intervention, the results revealed statistically significant improvement

in all the domains of family interaction patterns in the experimental group; reinforcement ($P<0.001$); social support ($P<0.001$); role ($P<0.001$); communication ($P<0.001$); cohesiveness ($P<0.001$) and leadership, compared to the control group (Table 2). These findings are evidence that the Family Intervention Package was effective in bringing about changes in family interaction

b. Level of Change in Deficits after Treatment

Table 3: Description of Deficits over the Period

Sl. No	Variables	During Treatment		6 Months Follow-up	
		EG	CG	EG	CG
1	Physical	15 (30%)	8(20%)	30(60%)	16(40%)
2	Neurological	-	-	2(4%)	-
3	Psychological	-	-	1(2%)	-
4	Physical and Neurological	2(4%)	8(20%)	4(8%)	10(25%)
5	Physical and Psychological	20(40%)	14(35%)	11(22%)	7 (18%)
6	Physical, Neurological and Psychological	13(23%)	10(25%)	1(2%)	7(18%)
7	None	-	-	2(4%)	-

Table 3 shows various forms of deficits among EG and CG during the hospitalisation and 6-month follow-up periods. Nearly 40% in EG and 35 % in CG had both physical and psychological deficits during treatment in the hospital. The comparison of nature of deficits found physical deficits to be high in both EG (60%) and CG (40%) over the 6-month period.

c. Occupational Functioning (6 Months after Intervention)

Table 4: Occupational Functioning (6 Months after Intervention)

Sl. No	Variables	EG	CG
1	Attending previous work	11(22%)	3(8%)
2	Change in work	7(14%)	7 (18%)
3	Not attending work	32(64%)	30(80%)

Table 4 shows the change in the occupational functioning of persons in both the groups. 80% of CG and 64 % of EG cases did not attend work even after 6 months of treatment. A few people, i.e., 22 % in EG and 8 % in CG, were doing the same

work they used to do earlier. 14% of EG and 18% of CG persons changed their occupations.

DISCUSSION

This was one of the first studies to use a scientifically researched Family Intervention Package for the families of survivors of head injury in India. The study aimed at evaluating the efficacy of the Family Intervention Package on acquired head-injury cases in India. Motor vehicle accidents were the main cause of head injury in the study. Most of the survivors were in the prime of their lives and were working prior to the accident.

The multi-component FIP package included education, psychological support, problem-solving and skills-building sessions, and information on community resources. The FIP was found to be significantly effective in improving the levels of functioning of persons with head injury in the areas of leadership, communication, role, reinforcement, cohesiveness, and social support systems among the families of the experimental group as compared to the control group, over the 6-month follow-up period.

Family adaptation is the central concept in understanding the focus of the family's struggle to manage a member with a head injury over time. The outcome of family intervention is to bring a new level of balance, harmony, coherence, and a satisfactory level of functioning to a family following head injury. The level of family adaptation in response to a crisis situation is determined by the pile-up of demands on or in the family system created by the crisis situation, life cycle changes, and unresolved strains; (McCubbin, 1993). The psychosocial care providers must be aware that the process of family adaptation to head injury continues for many years after the initial medical and rehabilitation services.

Post head injuries, nearly three-fourths of the persons in both groups in the current study, were not attending work. Change in occupation was seen in a few cases. This denotes that accidents bring occupational loss. Kersel et al (2001) and several others (Blanchard et al, 1995; O'Neil et al, 1998) calculated post-injury loss of employment to be 70 %. There was significant association between nature of the work being done at present and the effect of loss in daily functioning abilities. Ability to be functional in day-to-day living situations is an indicator of employability. The level or degree of functionality may determine the level of employability too. Blanchard and associates (1995) stated that almost half

of the survivors of head injury are at noticeable risk of developing social and occupational difficulties, and increased subjective distress and role impairment. The role function impairment was noticed particularly in work situations and during participation in social activities. TBI can often change the person's career direction in terms of the work role and earnings lost (Jacobs, 1988). Due to the incurrance of behavioural, cognitive, and physical impairments, returning to former employment becomes impossible (Cifu et al, 1997). Moreover, age, sex, nature of brain trauma and extent of disability can influence an individual's ability to resume a career (Ogden, 1987).

Brain injury produces changes in behaviour in the spectrum of attentional, perceptual, cognitive, emotive, and executive aspects of functioning, often affecting more than one domain and to varying degrees (Garoutte & Aird, 1984). The patterns of behavioural dysfunction may also vary considerably (Tabaddor et al, 1984). In the current study, both groups had multiple types of physical, psychological, and neurological deficits. However, there were more cases with physical deficits - 60% and 40 % in both EG and CG - over the 6-month follow-up period.

CONCLUSION

This study provides evidence that the Family Intervention Package is beneficial in improving the family functioning of persons with ABI or TBI. The FIP should be made a part of the treatment in a multi-disciplinary setting with medical management. The multi-disciplinary team dealing with persons with head injury should recognise the importance of the multi-component FIP for survivors and their families.

Limitations

Generalisation of the findings was not possible due to the smaller sample size. The FIP model needs to be replicated with larger sample groups, and the impact needs to be assessed with other larger measures such as social functioning and occupational functioning of family members and survivors. Future studies should also include survivors in the treatment programme.

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