# Efficacy of Caregivers' Intervention on Recovery of Head Injury Cases in India

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## Abstract

**Background** Patients with head injury are discharged from hospitals in a dependent state. In the home care settings, the caregivers have to take care of the patients. In India, there is scarcity of data on interventions of family caregivers of persons with head injuries.

**Objective** To assess the efficacy of an instructional module for caregivers of patients with head injury on recovery of the patients.

**Method** The study was performed at the Neuro-Surgery Department of Post Graduate Institute of Medical Education and Research (PGIMER), Chandigarh, India. Total 82 patients with 41 each in experimental and control groups and their caregivers were included in the study. The caregivers of patients in experimental group were demonstrated procedures related to care of a dependent patient. An instructional module containing guidelines regarding personal hygiene, catheter care at home, prevention of bedsores, tracheostomy suctioning at home, range-of-motion exercises, care of surgical wound, and discharge instructions regarding medication and follow-up was given to the caregivers in experimental group. The efficacy of intervention was assessed on occurrence of fever, chest infection, eye infection, bedsores, wound infection, constipation, urinary tract infection, deep vein thrombosis, length of stay, and readmission in hospital in both the groups.

**Results** Occurrence of fever, constipation, and length of stay were reduced significantly in experimental group. A reduction in the rates of chest infection, bedsore development, wound infection, and urinary tract infection were also noted in experimental group.

**Conclusion** The study shows that training the caregivers of head injury patients enhances the recovery and prevents complications in the patients.

**Keywords**
- head injury
- educational intervention
- recovery outcomes

## Introduction

Traumatic brain injury (TBI) is a silent epidemic of modern times and a serious health concern. At the national level, nearly 2 million people sustain brain injuries, 0.2 million lose their lives, and nearly 1 million need rehabilitation services every year. Majority of these cases are young males.[1] In India, deaths and injuries have increased by nearly two (50,700–98,254) and four times (109,100–465,282) during the period 1991 to 2005, respectively.[2]

Traumatic brain injury survivors are often left with significant cognitive, behavioral, and communicative disabilities.[3] Because brain injuries affect a significant proportion of young people, caregiving poses distinct challenges as survivors often require long-term care throughout their expected lifetimes.[4] Complications such as muscle contractures, pressure sores, and unnecessary aggressive behavior are common in TBI patients. Caregivers' distress is known to increase with time.[5]

In India, TBI patients are transferred from tertiary care hospitals to local hospitals as soon as they are medically stable. Many are looked after by the family caregivers. However, very few are prepared to meet the challenges of caring for their loved ones at home. They lack nursing skills,

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knowledge of available help and its sources, coping skills, and support systems. A structured teaching by the health care professionals may help patients prepare for discharge and help them ease the tension in the home environment.[6]

Extensive literature on family needs indicates that family members rate the needs for information and emotional support very high.[7] However, many important needs are identified as unmet.[8] An important question to consider is that 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 health care and a demanding psychosocial rehabilitation process?[9]

Although many researchers agree that family members are adversely affected by brain injury and are likely to benefit from treatment,[10,11] 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 rigor required to recruit families, conduct a prolonged intervention, and collect data. There is limited literature on interventional studies in the Indian setting regarding interventions for families of TBI. The aim of this study, therefore, was to test the efficacy of instructional module for caregivers on recovery of TBI patients.

## Methodology

### Setting

The study was performed at Neurosurgery Inpatient Unit of Advanced Trauma Centre of Post Graduate Institute of Medical Education and Research (PGIMER), Chandigarh.

### Sample

Eighty-two patients with moderate and severe head injury were selected. Inclusion criteria were patients with acute head injury with no evidence of fever, chest infection, eye infection, bedsores, wound infection, urinary tract infection (UTI), constipation, and deep vein thrombosis (DVT) at the time of admission. Exclusion criteria were cranioplasty patients and patients with evidence of fever, chest infection, eye infection, bedsores, wound infection, UTI, constipation, and DVT at the time of admission. The patients were randomly assigned with 41 patients and 41 caregivers each in experimental group (EG) and control group (CG), respectively.

### Measures

Sociodemographic data of the patients and caregivers and clinical profile and recovery outcomes of patients were obtained by a self-prepared interview schedule. Instructional module in the form of booklets comprising seven domains was prepared. These were maintenance of personal hygiene, prevention of bedsores, catheter care, tracheostomy suctioning, range-of-motion exercises, care of surgical wound at home, discharge instructions on diet and medication, and follow-up. Recovery outcomes assessed were fever, chest infection, eye infection, infection over surgical site, UTI, constipation, DVT, length of stay, and readmission. Validity of the tool was established. A pilot study was conducted to check the reliability and feasibility of the tool.

### Ethical Consideration

Approval of the research protocol was sought from the ethics review committee of PGIMER, Chandigarh. Written permission was taken from the department head prior to data collection.

### Procedure

Screening of case files was done, and patients were screened for baseline infection. At the initial intake session, the researcher confirmed eligibility and interest in participation, identified the primary caregiver, and obtained informed consent from all participants (caregivers). The sociodemographic data of patients and caregivers and also clinical profile of the patients were obtained. Procedures regarding care of dependent patients were demonstrated to caregivers in EG, and instructional module regarding care of patients with head injury was also given to them. Comprehensive care was provided to EG patients by caregivers. CG patients received routine care. Recovery outcome variables were assessed from the day of admission till discharge and on first follow-up (15 days after discharge) in neurosurgery OPD.

Recovery outcome data were collected from case files, reports of patients (tracheal culture for chest infection if patient had fever, excessive foul-smelling secretions, and abnormal chest sounds, and urine culture for UTI if patient had fever and increased pus cells in routine urine examination) and by measuring body temperature, monitoring respiratory rate, auscultating chest sounds, inspecting external eye structures for redness/discharge/ulceration and inflammation, assessing surgical wound for redness/edema/discharge/presence of pus/wound dehiscence, and observing frequency of stool and pressure sites for redness/skin breakdown.

## Results

### Sociodemographic Profile of Patients

The patients in both the groups were homogenous as per age, sex, marital status, educational status, religious background, occupation, and lifestyle habits of the patients ($p > 0.05$) (►**Table 1**).

### Sociodemographic Profile of Caregivers

Caregivers in both the groups were homogenous as per the age, marital status, educational status, religious background, occupation, and per capita income ($p > 0.05$), except sex ($p < 0.05$) as EG had significantly more male caregivers.

### Clinical Profile of Patients

Most patients (EG 78% and CG 75%) had injury due to roadside accident. Both the groups were homogenous in terms of cause of injury, Glasgow coma scale (GCS) at the time of admission, method of airway management, comorbidity, and number of antibiotics received ($p > 0.05$). Maximum percentage of the patients (88%) received injection cefuroxime. Injection amikacin, an aminoglycoside, was used in combination with other drugs in both the groups.

**Table 1** Sociodemographic profile of patients, *N* = 82

| Sociodemographic variable | Control group *N* = 41 | Experimental group *N* = 41 | $\chi^2$, df, *p* value |
|---|---|---|---|
| | *n* (%) | *n* (%) | |
| Age (y) | | | |
| 1–20 | 4 (10) | 6 (15) | 0.99, 3, 0.80 |
| 21–40 | 22 (53) | 22 (54) | |
| 41–60 | 13 (31) | 10 (24) | |
| 61–80 | 2 (6) | 3 (7) | |
| Mean age ± SD | 36.37 ± 13.249 | 36.37 ± 15.938 | |
| Range | 17–78 | 14–80 | |
| Sex[a] | | | |
| Male | 38 (92) | 36 (88) | 0.139, 1, 0.71 |
| Female | 3 (8) | 5 (12) | |
| Marital status[b] | | | |
| Unmarried | 7 (17) | 9 (22) | 1.34, 2, 0.59 |
| Married | 34 (83) | 31 (76) | |
| Widow/widower | 0 (0) | 1 (2) | |
| Educational status | | | |
| Illiterate, primary, and middle | 21 (51) | 18 (44) | 0.440, 1, 0.51 |
| Matric and above | 20 (49) | 23 (56) | |
| Religion | | | |
| Hindu | 25 (61) | 28 (69) | 0.48, 1, 0.49 |
| Others (Sikh, Muslim, and Christian) | 16 (39) | 13 (31) | |
| Occupation | | | |
| Regular employee/business/private job | 18 (45) | 8 (19) | 6.79, 3, 0.08 |
| Laborer | 11 (27) | 14 (34) | |
| Agriculture | 6 (14) | 6 (15) | |
| Unemployed (student, not working and housewife) | 6 (14) | 13 (32) | |
| Lifestyle habits[b] | | | |
| Smokers | 2 (5) | 0 (0) | 6.55, 3, 0.06 |
| Alcoholics | 1 (2) | 7 (17) | |
| Smoker and alcoholics | 7 (17) | 8 (20) | |
| Nonsmokers and nonalcoholics | 31 (76) | 26 (63) | |

Abbreviation: SD, standard deviation.
[a]Yates's continuity correction,
[b]Fisher's exact test.

### Effect of Intervention in Performing Various Procedures in Experimental Group

►**Table 2** represents the difference between various observations in performance of various procedures by EG caregivers on their patients, highlighting improvement on repeated re-demonstrations till 100% skill attainment. Nine EG patients died before follow-up, so only 32 caregivers in EG were analyzed for their skills in performing various procedures.

### Efficacy of Intervention on Recovery of the Patients during Hospital Stay

►**Table 3** depicts the assessment of recovery outcome variables during the hospital stay of patients. Patients who did not develop fever were significantly more in EG ($p = 0.05$). Patients with stay of less than 5 days in advanced trauma center (ATC) neurosurgery ward were significantly more in EG ($p < 0.05$) compared with CG. Rate of bedsore development and wound infection was 9.8% and 4.9%, respectively, in CG whereas it was 0% in EG.

**Table 2** Effect of intervention in performing various procedures among the caregivers in experimental group, *N* = 32

| Aspects of care | Experimental group | | | | | |
|---|---|---|---|---|---|---|
| | Observation 1 | | Observation 2 | | Observation 3 | |
| | *n* (%) | *N* | *n* (%) | *N* | *n* (%) | *N* |
| Positioning the patient | 17 (53) | 32 | 10 (67) | 15 | 5 (100) | 5 |
| Performing eye care | 12 (38) | 32 | 15 (75) | 20 | 5 (100) | 5 |
| Performing oral care | 7 (22) | 32 | 17 (68) | 25 | 8 (100) | 8 |
| Performing back care | 10 (31) | 32 | 15 (68) | 22 | 7 (100) | 7 |
| Performing female catheter care | 0 (0) | 2 | 0 (0) | 2 | 2 (100) | 2 |
| Performing male catheter care | 10 (33) | 30 | 10 (50) | 20 | 10 (10) | 10 |
| Performing tracheostomy suctioning | 10 (31) | 32 | 10 (45) | 22 | 12 (10) | 12 |
| Performing range of motion exercises | 10 (31) | 32 | 10 (45) | 22 | 12 (10) | 12 |

**Table 3** Assessment of recovery outcome variables during the hospital stay of patients, *N* = 82

| Variables | Control group, *n* (%) | | Experimental group, *n* (%) | | $\chi^2$, df, *p* value |
|---|---|---|---|---|---|
| | Yes | No | Yes | No | |
| Fever | 9 (22) | 32 (78.0) | 2 (4.9) | 39 (95.1) | 3.78, 1, 0.05* |
| Chest infection[a] | 5 (12.2) | 36 (87.8) | 1 (2.4) | 40 (97.6) | 1.618, 1, 0.20 |
| Eye infection | 0 (0) | 41 (100) | 0 (0) | 41 (100) | |
| Bedsores | 4 (9.8) | 37 (90.2) | 0 (0) | 41 (100) | 4.205, 1, 0.12 |
| Wound infection[b] | 2 (4.9) | 39 (95.1) | 0 (0) | 41 (100) | 2.05, 1, 0.49 |
| UTI | 7 (17.1) | 34 (82.9) | 1 (2.4) | 40 (97.6) | 3.46, 1, 0.06 |
| DVT | 0 (0) | 41 (100) | 0 (0) | 41 (100) | |
| Length of stay ≤ 5 days in ATC neurosurgery ward | 33 (80) | 8 (19.5) | 40 (98) | 1 (2.43) | 4.49, 1, 0.03[c] |

Abbreviations: ATC , advanced trauma center; DVT, deep vein thrombosis; UTI, urinary tract infection.
[a]Fischer's exact test
[b]Yates's continuity correction
[c]Statistically significant.

**Table 4** Assessment of recovery outcome variables of the patients at follow-up in neurosurgery OPD (15 days after discharge), *N* = 64

| Variables | Control group *N* = 32, *n* (%) | | Experimental group *N* = 32, *n* (%) | | $\chi^2$, df, *p* value |
|---|---|---|---|---|---|
| | Yes | No | Yes | No | |
| Fever | 0 (0) | 32 (100) | 0 (0) | 32 (100) | |
| Chest infection | 0 (0) | 32 (100) | 0 (0) | 32 (100) | |
| Eye infection | 0 (0) | 32 (100) | 0 (0) | 32 (100) | |
| Bedsores[a] | 7 (21.9) | 25 (78.1) | 2 (6.3) | 30 (93.7) | 2.06, 1, 0.15 |
| Wound infection | 0 (0) | 32 (100) | 0 (0) | 32 (100) | |
| UTI | 0 (0) | 32 (100) | 0 (0) | 32 (100) | |
| Constipation[b] | 5 (15.6) | 27 (84.3) | 0 (0) | 32 (100) | 5.42, 1, **0.02**[c] |
| DVT | 0 (0) | 32 (100) | 0 (0) | 32 (100) | |
| Readmission | 0 (0) | 32 (100) | 0 (0) | 32 (100) | |

Abbreviations: DVT, deep vein thrombosis; UTI, urinary tract infection.
[a]Fischer's exact test, [b]Yates's continuity correction, [c]Statistically significant.

### Efficacy of Intervention on Recovery of the Patients 15 Days after Discharge at First Follow-up in Neurosurgery OPD

►**Table 4** depicts the recovery outcome variables of the patients assessed 15 days after discharge at first follow-up in neurosurgery OPD. Nine patients in each group died before follow-up, so only 64 patients were analyzed, and 15.6% patients developed constipation in CG whereas no patient had constipation in EG ($p < 0.05$). The number of patients who developed bedsores was less in EG (6.3%) as compared with CG (21.9%).

## Discussion

Most TBI patients after getting their condition stabilized are discharged from the hospital. Quite often they are looked after by the formal or informal caregivers in their home care settings. Therefore, it is very important that the caregivers should be trained to take up these responsibilities. As such, there is no system of training of these caregivers.

Donelan and colleagues explored this issue more than a decade ago. Family caregivers reported receiving little training in how to manage wound care, pumps and machines at the bedside, and medications.[12] Other studies have looked at these tasks in the context of specific populations. To our knowledge, in India, there is hardly any study on intervention for the caregivers.

This study was performed to teach the caregivers using demonstrations and an instructional module. It aimed at facilitating caregivers to perform the routine procedures regarding care of dependent head injury survivors. The instructional module was developed to assist caregivers in providing adequate, safe, and efficient care to their patients in the home setting, to improve patient's quality of life and to prevent complications. All the procedures were demonstrated, and then repeated return demonstrations were taken from each caregiver. These procedures were eye care, oral care, back care, catheter care, position change, tracheostomy suctioning, and range-of-motion exercises. They were motivated to do the procedures during their hospital stay as well as after their patients got discharged from the hospital. In fact, because of the shortage of nurses, caregivers are often also involved in providing care to their patients in the hospitals itself. In this study, they were trained using a structured program. Return demonstrations were taken until they were perfectly performing the procedure.

Training the caregivers through demonstrations and instructional module was found to be effective in reducing the rates of fever, bedsores, chest infection, UTI, constipation, wound infection, and length of stay among the EG patients as compared with the CG patients during hospital stay and over the 15-day follow-up period.

In a survey done by Reinhard et al, 57% of family caregivers performing medical/nursing tasks revealed that they did not have a choice in taking on caregiving tasks because there was no one else to do it or insurance would not cover a professional's help. For these caregivers, the most frequently cited reason (43%) was feelings of personal responsibility ("no one else to do it or insurance would not cover payment for a professional").[13] In this study also, because most families (87%) had low per capita income (Rs. 2,001–4,000/month), these families could not afford to avail the health care facilities in local primary care hospitals for a long time and so had to care for their patient themselves.

Reddy et al conducted a study to test the efficacy of a family intervention package (FIP) with caregivers of persons with head injuries. 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 EG patients as compared with the CG patients, over the 6-month follow-up period.[14] In this study also, training the caregivers was found to be effective in enhancing the recovery of the patients in terms mentioned earlier.

Every health care personnel must feel personally responsible for ensuring that the patients and families understand how to perform the challenging tasks related to care of a dependent patient. Physician, nurses, rehabilitation therapists, and others must encourage family caregivers to ask questions and give them information for additional help.[13] Supported by The John A. Hartford Foundation, a broader panel of experts, has identified the urgent need for health care professionals to better support family caregivers through evidence-based information and tailored support.[15]

## Conclusion

This study provides evidence that the instructional module along with training of caregivers through demonstrations is beneficial in enhancing the recovery and preventing complications in head injury patients. Teaching the caregivers regarding care of a dependent patient should be made one part of the treatment in hospital. The multidisciplinary team dealing with patients with head injury should recognize the importance of the multicomponent instructional module for survivors of head injury and their families.

There were few limitations of the study including small sample size, and it was not possible to observe the practices of caregivers directly while caring for their patients in the home setting. Carrying out the study on larger sample size is recommended. Long-term follow-up should be done to evaluate the effectiveness of intervention.

**Conflict of Interest**
None.

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