

# Home-Based Palliative Care in Neurotrauma

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## ABSTRACT

Families usually offer home care for those with head injuries in India, since there aren't many professional long-term care institutions. In this situation, the caregivers' mental health becomes a serious issue. Regretfully, society and healthcare providers frequently ignore this factor. As such, caregivers are susceptible to mental health illnesses like anxiety, depression, and other mental health problems. Head injury victims' recuperation and rehabilitation are negatively impacted by this circumstance. The authors of this study have reviewed relevant literature to determine the scope and frequency of this problem among family caregivers of patients with neurotrauma.

To properly manage these issues, the authors have identified several possible actions that the community and the neurosurgeon treating the patient can take.

Their objective is to educate the neurosurgeon and other medical professionals about this issue and its various ramifications.

## Key words:

**Head injury, Neurotrauma, Mental Health, Anxiety, Depression, caregiver**

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## INTRODUCTION

One of the most important parts of a neurosurgeon's duties at well-run hospitals is treating head injuries. Unfortunately, the prevalence of head injuries has increased globally because of the fast expansion of both urban and rural areas. For people under 45, trauma has emerged as the primary cause of death and disability. Many patients with moderate to severe brain injuries are discharged in situations that compel them to rely on family members for support with everyday life tasks, even though improvements in surgical methods and critical care units have decreased mortality rates.

Some of these patients are discharged home with tracheostomy tubes, indwelling catheters, nasogastric or gastrostomy tubes, and/or low Glasgow Coma Scale (GCS) scores. Long-term hospital beds for these patients are difficult to come by in India's already overworked healthcare system. Professional long-term care institutions, meanwhile, are essentially non-existent. Professional nursing home care is still a relatively new idea and is only accessible in large cities at exorbitant prices. As a result, the patient's close relatives are usually in charge of providing home care. Parents and spouses are typically the primary caretakers. For people who frequently have different degrees of comprehension, education, and patience for such obligations, this



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is a difficult undertaking.

## REVIEW OF LITERATURE

Numerous studies show that medical professionals frequently prioritize the demands of their patients over those of their family members.

Kreutzer, Jeffrey S. et al., for instance, investigated the type of family hardship in similar circumstances and discovered that more than 50% of the survivors and caregiver family member suffered from anxiety and depression (1).

Torregrossa et al. discovered that, especially in cases of severe injury, behavioural dyscontrol, neuropsychiatric, and affective symptoms are rather common and incapacitating outcomes of TBI (2). A multidisciplinary approach is needed to better understand the epidemiology and phenomenology and manage these issues. Multidimensional and symptom-specific neuropsychological measures that are valid and reliable are helpful in evaluating these diseases. When working with these fragile patients and their caregivers, it is important to keep in mind that emotional, neurocognitive, and BD often co-occur with other posttraumatic neuropsychiatric disorders. Furthermore, a symptom-specific approach that combines pharmacologic and non-pharmacologic (i.e., behavioural, psychological, and environmental) methods is typically needed. These therapies have the potential to significantly alleviate posttraumatic emotional and behavioural impairments in severe TBI patients and their families when implemented appropriately.

86 caretakers of patients with ABI were enlisted by Corallo F et al (3). Two seasoned psychologists used Olso's Family Adaptability and Cohesion Rating Scale (FACES IV) to study how families work. Only flexibility ( $p = 0.05$ ) revealed a significant difference in the general group correlation. In particular, male caregivers-especially sons-were more adaptable. Despite the ABI incident, the majority of the components that define family functioning, such communication stayed the same. Their results showed that family member were more distressed than parents, and once more, there was no relationship between distress levels and the severity of the damage.

In the study by Douglas and Spellacy (4), who utilized the Self-Rating Depression Scale (5) for assessment, the prevalence of parental depression (77%) was higher than that of spousal depression (47%).

The distress levels of parents, spouses, and other caregivers were similar, according to a different study by Kreutzer, Jeffrey S. et al (6). Caring for survivors with worse functional level, greater monitoring, lower life satisfaction, and excessive alcohol use was linked to high-

er caregiver distress. Caregivers frequently experience somatic symptoms, anxiety, and depression. The results support the significance of clinical care systems that attend to the long-term needs of survivors and caregivers.

Sluys, K.P. et al. (7), used HRQL (health related quality of life reports) from the children and their parents with proper agreement. Lower scores on parent proxy reports and child self-reports of HRQL following injury were linked to parents' worse mental health. Clinical care should take into account the potential link between children's HRQL and their parents' mental health state, as shown by the current study.

Wade et al. (8) investigated whether parents of children with traumatic brain injuries (TBIs) experience more burden and distress as a result of their injuries. Social resources moderated the family function, but attrition was higher in families with serious injuries. In follow-up, families of children with severe brain injury and few resources reported declining functioning. It is impossible to overstate the significance of family function in these situations.

According to qualitative analysis by Carlozzi et al (9), social health accounted for 42% of caregivers' comments, with emotional health (34%), physical health (11%), cognitive health (3%), and feelings of loss (9%), which are related to the care recipient's future or potential changes or to the caregiver, being the other most significant issues. Concerns that were discussed were caregiver-specific and not fully assessed by current patient-reported outcomes (PROs). These included caregiver strain (burden, stress, feeling overwhelmed, etc.), anxiety related to the caregiver role (reinjury concerns, worry about leaving the person alone, etc.), and feelings of loss.

According to Ponsford et al. [10], there were no appreciable differences in anxiety and depression between parents and spouses, and the degree of the injury had no bearing on the depression.

59.2% (n=71) of the 120 caregivers in the study by Lee Y et al. (11) were female. 54.2% of the caregivers had a psychiatric diagnosis, with depressive disorders accounting for the most common diagnosis (25.8%), followed by anxiety disorders (17.5%) and insomnia disorder (15.8%). Using logistic regression analysis, we discovered three significant related factors: weaker family support (APGAR scores) (OR=0.82; 95% CI, 0.71-0.94; p<0.01), higher suicide risk (SAS) (OR=1.10; 95% CI, 1.05-1.16; p<0.001), and the use of anxiolytics/hypnotics (OR=5.58; 95% CI, 1.84-16.96; p<0.01). The most common psychiatric diagnosis among those who cared for patients with depressive disorder was depression. In order to provide appropriate assistance and therapy for caregivers of patients with depression, early mental diagnosis is essential and may enhance the quality of life for caregivers.

69 primary caregivers of persons with severe traumatic brain injury (TBI) were evaluated by Marsh NV et al. (12) one year after the injury. Questionnaires on the individual with TBI's physical, cognitive, emotional, behavioral, and social functioning were filled out by caregivers. Psychosocial functioning, subjective burden, and objective load of caregivers were also evaluated. More over one-third of the caregivers had clinically significant levels of despair and anxiety. In a similar vein, poor social adjustment was observed by 25% of the caregivers. The degree of subjective suffering brought on by these changes did not consistently correlate with the prevalence of different kinds of objective load. Caregivers had the most discomfort due to the emotional challenges of the person with TBI, including

their anger, indifference, and reliance. The loss of personal leisure time caused the greatest grief among caregivers when it came to the effects of caring on their own life. Regression analysis results showed that the most powerful predictors of caregiver burden were the physical disability, number of behavioral issues, and social isolation of the individual with TBI. There is discussion of the effects that providing care for an individual with severe TBI might have on the extended family.

Kjeldgaard et al (13) were included 24 studies in research. More severe injuries, functional limitations (such as reduced physical and cognitive functioning), and poorer mental health were all associated with higher caregiver burden. More time spent providing care, worse mental health, and unmet needs were all variables associated with caregivers. There was conflicting or ambiguous evidence for a number of predictor factors. The findings indicate which caregivers are susceptible to caregiver stress and suggest a number of possible intervention areas to avoid caregiver burden.

Sander et al. (14) have stated after their research study that it's important to remember that caregiver stress and strain are linked to poor outcomes for the TBI patients they look for. Therefore, the mental health of the survivor's family and home caregivers is also related to the survivor's satisfactory recovery. Most caregivers for people with TBI report suboptimal family functioning, according to Nabors et al. [15]. Rasmussen et al (16) study showed that TBI has long-lasting effects on patients' general mental health and emotional functioning, regardless of the degree of the damage. It also has some effect on family members. Since the patients' resilience, self-efficacy, mental health, and general health were all far poorer than those of their family members, the patients bore the majority of the illness burden. Some depressive symptoms were noted by the family members. The individuals' assessments of balanced family functioning were comparable. Family satisfaction was rated as moderate and family communication as good. Family-related characteristics were linked with sex, sadness, anxiety, and resilience.

## DISCUSSION

Regardless of the hospital or location, long-term care facilities and home nursing services are severely lacking in India. Due of overcrowding, many neurosurgery departments frequently have to send patients who require continuous nursing and rehabilitation care home. Many of these families have low socioeconomic means and are from rural areas.

The rehabilitation of brain injury survivors can improve caregivers' mental health and solidify family ties, according to research by Syed Hasan et al. (17). Additionally, Carlozzi et al. (9) analysed nine focus groups with caregivers of people with moderate to severe brain injuries to identify important areas of health-related quality of life that are important to them. According to their research, social health was the top worry for caregivers (42%), followed by emotional, physical, cognitive, and loss-related health. Several studies that addressed topics including TBI care, caregiver responsibilities, and family requirements were found through the literature search by Azman et al (18). Studies on caregiver duties, the mental and physical challenges, and the general family requirements involved in the care of TBI patients were the primary emphasis of this review's topic. According to research, caregivers who receive little assistance will have difficulties related to their physical and emotional well-being.

Therefore, in order to improve the social functioning and well-being of the caregiver, health professionals must fulfil their responsibility in helping the family attend to their social functions in addition to their nursing responsibilities.

These variables must be considered as we suggest ways to support patients and their families.

Before being released, attendants must get sufficient training and confidence-building exercises. Clear instructions in the attendants' native tongue should be given for feeding tube use, tracheostomy management, and catheter maintenance. In this process, the attending neurosurgeon and the nursing personnel are essential.

In addition to evaluating the patient, the attending neurosurgeon should interact with the family and caregivers during outpatient department (OPD) appointments. It is critical to identify and send caregivers to psychiatry or psychology as soon as they show symptoms of anxiety or sadness. Regardless of the extent of the patient's damage, this recommendation should be made because research indicates that caregiver discomfort is not correlated with the severity of the injury. Nongovernmental organizations (NGOs) and social support groups can assist in establishing a friendly atmosphere for these patients' at-home care. Training in the rehabilitative management of these patients should be provided to the medical professionals and nursing personnel employed by outlying hospitals. Caregiver worry can be considerably reduced by transporting these patients to nearby hospitals for standard treatment and supervision. In addition to helping with patient follow-up, having regular phone talks with caregivers and offering support can greatly enhance their mental health.

### CONCLUSION

A significant problem that is frequently disregarded is anxiety and despair in those who care for people who have had brain injuries. Most of the research suggests that the severity of the brain injury has no bearing on the caregivers' anxiety and depression levels. Furthermore, studies reveal that caregiver stress has a detrimental effect on the survivor's recuperation. It is crucial to give caregivers the necessary training and confidence-boosting skills, identify depressive symptoms early, lead support groups, and have regular phone discussions to overcome these obstacles. The lives of caregivers dealing with these problems can be significantly improved by doing these actions.

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