

# Home Care of Patients with Head Injury: Are We Neglecting the Caregivers?

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Indian J Neurotrauma 2017;14:83–85

## Abstract

In the absence of professional long-term care facilities in India, home care to patients with head injury is usually provided by family members. In this scenario, the mental health of the caregivers remains an important issue. This factor is constantly neglected by the health care providers and the society alike. With the result, the caregivers are prone to depression, anxiety, and other forms of mental illnesses. This also has a negative impact on the recovery and rehabilitation of the head injury survivor. In this article, the authors have reviewed relevant literature to find out the extent and prevalence of this problem among home caregivers of patients with head injury. The authors have also highlighted the possible measures that the treating neurosurgeon and the society can take for effective management of these issues. Their aim is to make the neurosurgeon and other health care providers aware of this issue and its various ramifications.

## Keywords

- ▶ caregiver
- ▶ depression
- ▶ anxiety
- ▶ head injury

## Introduction

Management of head injury continues to be a vital part of neurosurgeons work in most organized setups. The rapid development, both in urban and rural areas, has come at the price of increasing incidence of head injury all over the world. Worldwide, now trauma has emerged as the leading cause of death and disability for the population younger than 45 years.<sup>1</sup> The advent of better operative and intensive care facilities has meant that mortality rates have gone down. However, many patients with moderate and severe head injury are discharged in a state in which they are dependent on family members for their day-to-day activities of living. Some of these patients are discharged with low Glasgow coma score (GCS) on tracheostomy tubes, indwelling catheters, and nasogastric or gastrostomy tubes. In India, the already overburdened health care system is unable to provide a hospital bed for these patients beyond a time limit. At the same time, professional long-term care facilities are virtually nonexistent. Home care professional nursing is still an emerging concept available at a prohibitive cost only in metros. Therefore, the responsibility of home care lies usually with the patient's

immediate family members. In their practice, we usually see spouses and parents as the major home care providers. This is a daunting task for people who have varied levels of understanding, education, and patience for this job.

## Extent of the Problem

In various studies, it has been constantly noted that health care providers focus mainly on the patients while ignoring the needs of the family that cares for the patient.<sup>2</sup> Initially, Mauss-Clum and Ryan<sup>3</sup> investigated the nature of family distress in such cases and found that 80% of the caregiver wives are depressed along with 57% of the survivors. Linn et al<sup>4</sup> used a standard outcome measure in the form of Symptom Checklist-90 (SCL-90)<sup>5</sup> to study 60 spouses and survivors at a weekend retreat. They found that 73% of spouses and 70% of survivors exceeded the cutoff levels for depression. In terms of anxiety, 55% spouses and 50% survivors exceeded cutoff levels. Interestingly, no relationship was noted between the distress levels in the spouses and the severity of injury. Using Brief Symptom Inventory (BSI),<sup>6</sup> Kreutzer et al<sup>7,8</sup> studied 62 family members and found that 23% family members exceeded

received  
October 29, 2016  
accepted  
November 20, 2017

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Society of India

DOI <https://doi.org/10.1055/s-0037-1616033>.  
ISSN 0973-0508.

cutoff for depression. The criteria for clinically significant depression were met in 47% members; 32% of those interviewed exceeded cutoff for anxiety, 25% exceeded cutoff for somatization, and 33% exceeded the cutoff for Global Severity Index (GSI). They also noted that spouses showed greater distress levels as compared with parents, and injury severity was not related to the distress levels. Similar findings were elicited by Gervasio et al,<sup>9</sup> who also used BSI and found that 22% family members exceeded cutoffs for depression and 32% for anxiety. Cutoffs for somatization and GSI were exceeded in 17% and 23% members, respectively. They also found that spousal distress was more than parental distress and injury severity was not related to the distress levels. Many other studies that have addressed the caregiver needs, distress, and problems include those by Wade et al,<sup>10</sup> Campbell,<sup>11</sup> Armstrong and Kerns,<sup>12</sup> and Engli et al.<sup>13</sup>

Gillen et al<sup>14</sup> evaluated 39 mothers and 20 spouses using the National Institute of Mental Health Diagnostic and Interview Schedule (Revised). They found that one-half of the members met the criteria for major depressive disorder. Like previously mentioned studies, they found that injury severity was not related to the depression. However, there was no difference between spousal and parental depression in their study. Incidence of parental depression (77%) was more than that of spousal depression (47%) in the study by Douglas and Spellacy<sup>15</sup> who used the Self-Rating Depression Scale<sup>16</sup> for assessment. Ponsford et al<sup>17</sup> noted no significant differences between spouses and parents regarding depression and anxiety and that the depression was unrelated to the severity of injury. Kreuzer et al<sup>18</sup> used BSI-18<sup>19</sup> as the primary outcome measure and found that the distress levels among spouses, parents, and other caregivers were comparable. They also found that levels of depression, anxiety, and somatic symptoms were equally prevalent. The proportion of participants with one, two, and three elevations was 17.9, 5.5, and 10.6%, respectively. Approximately two-thirds of participants had no scores exceeding cutoffs. A multitude of other studies also document that the rates of depression in caregivers of head injury are in the order of 25 to 61%.<sup>20-23</sup> Wade et al<sup>24</sup> studied whether parents of children with traumatic brain injuries (TBIs) report increased injury-related burden and distress. Attrition was higher in families in the severe injury group, but the family function was moderated by social resources. Families of children with severe brain injury and low resources reported deteriorating functioning in follow-up. The importance of family function in these cases cannot be overestimated. Nabors et al<sup>25</sup> noted that most caregivers of individuals with TBI report unhealthy family functioning. Ennis et al<sup>26</sup> reported that caregiving is associated with stress due to the intensity of continuous care being provided at all times. This may be associated with adverse cognitive, emotional, and other impairments in the caregiver. It is pertinent to note that caregiver burden and stress is also associated with negative outcomes in individuals with TBI whom they care for. Such findings have been noted by Sander et al.<sup>27</sup> Hence, satisfactory recovery of the survivor is also linked to the mental well-being of his/her family and home caregivers.

## What Can We Do to Help?

Regardless of the hospital and the place, we are well aware of the acute lack of long-term care facilities and domiciliary nursing in India. Most neurosurgical departments in India are overburdened and have to discharge patients who require nursing and rehabilitative care at home. The families usually hail from rural areas and have weak socioeconomic background. Syed Hasan et al<sup>28</sup> have pointed out that recovery of the brain injury survivor can enhance the entire families' closeness and bonding as well as improve the mental status of the caregiver. Carozzi et al<sup>29</sup> identified the aspects of health-related quality of life that are relevant to caregivers by analyzing nine focus groups of caregivers of moderate and severe brain injury. Caregivers were most concerned about their social health (42%). Other important issues included emotional health, physical health, feeling of loss, and cognitive health. We will have to keep these factors in mind while we propose the following measures relevant to their patients and patients' families:

1. Adequate training and confidence building in the attendants prior to discharge. The instructions for catheter, tracheostomy, and feeding tube care should be clear and in the local language of the attendants. The attending neurosurgeon and nursing staff have an important role to play in this matter.
2. During OPD visits, the attending neurosurgeon should talk to the family and caretakers in addition to patient assessment. If the caretaker(s) show features of anxiety or depression, prompt recognition and psychiatry/psychology referral are warranted. This should be done regardless of the severity of the injury as most studies indicate that the severity of injury has no bearing on the distress in caretakers.
3. Social support groups/nongovernmental organizations (NGOs) can help in creating a feasible environment for the home care of such patients.
4. Physicians and nursing staff working in peripheral hospitals need to be trained in rehabilitative management of such patients. It is easier to transport these patients to local hospitals for day-to-day care and management. This can go a long way in alleviating anxiety in the caregivers.
5. Regular telephonic conversation with the caregivers and encouragement can go a long way in improving the mental health of caregivers besides helping in follow-up of the patient.

## Conclusion

Anxiety and depression in caregivers of head injury is a genuine problem often ignored in our setup. Most studies point out that the depression and anxiety levels do not depend on the severity of head injury. Studies also point out that this stress has a negative impact on the recovery of the survivor. Adequate training and confidence building in attendants, prompt recognition of signs of depression, support groups, and regular telephonic conversation can go a long way in helping people with these problems.

**Acknowledgments**

None.

**Conflict of Interest**

None.

**Financial Support**

None.

**Authors' Contribution**

The authors submit this review article as their original work. The author contributions are as under

1. Yawar Shoab: Concept, design, literature search, manuscript writing.
2. Amit Dagar: Manuscript review and editing.
3. Abraq Asma Reyaz: Manuscript review.

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