

Communicating with the caregiver in neurotrauma

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Neurotrauma, whether cranial or spinal is to be regarded as a family disease, affecting all the family members in some way or other. In case of cranial injury, patient him/herself is unaware or lacks insight compounding the overall stressful responsibility of the family. Unlike the developed and western countries that have well developed post-traumatic rehabilitation centres and organizations for the purpose, in India, the burden of caring such a patient falls on the immediate family. Caring for a vegetative patient, or one with emotional and behavioural problems, or a paraplegic poses a formidable challenge. In monetary terms, neurotrauma, unexpected as it is, can pull significant number of families below poverty line. Some of the challenges faced by family caregivers are documented in the literature. Caregivers report high levels of stress and poor physical and emotional health, as well as career sacrifices, monetary losses, and workplace discrimination¹. In the setting of a brain trauma, family caregivers face special challenges posed by the neurocognitive and neurobehavioral effects. Brain trauma patients make up a unique diagnostic and treatment group. The problem occurs out of the blue, is catastrophic, often compounded by other injuries, and by the need for transporting the patient to a suitable, equipped and affordable hospital. Following the sentinel event, ongoing limitations in physical and cognitive function and quality of life are prevalent and bring additional coping challenges for family caregivers. The needs of brain trauma patients differ from those of other trauma patients and often are unmet by existing resources. Even a mild head injury can produce disabling cognitive deficits, in which short term memory loss creates unique problems: patient forgets people he or she met minutes ago, there is risk of him/her losing track in the marketplace or movie hall, and reading a book becomes an ordeal wherein the reader has to repeatedly refer to pages read earlier. Driving skills may

be intact, but parking place may be forgotten. Neurocognitive changes are often challenging for the family member to assess, with reported symptoms including memory loss, impaired reasoning and processing, attention deficits, language difficulties, psychomotor deficits, and problems with working memory, such as the ability to sequence or perform multiple tasks at one time. Caregivers who do not understand neurocognitive changes find them daunting. The wife who does not understand may say, "He's just not paying attention to me," without realizing that her husband is no longer able to pay attention because of the neurocognitive effect of the brain injury. The physician will know that the underlying problem is damage to the curved, comma-shaped structure called the hippocampus, it will be difficult for the family members to understand. Family caregivers often have to deal with the patient's depression and other negative emotions, a task that is equally challenging as the physical care. Behavior and personality changes are also reported, including aggressive and impulsive behaviors. Caregivers who understand that the person cannot control or change behaviors are more resilient and find ways to cope (e.g., writing things down for the patient with memory loss or communicating information in smaller chunks). Most caregivers learn as events unfold, by seeking information from the physician or other health care providers, and it is beneficial to have a neuropsychologist involved in the patient's care.

One can extrapolate findings of Leavitt et al.² who analyzed themes from a brain tumor support group's meetings to understand experiences, needs, and supportive mechanisms of these patients. They also reported themes that include changes in family life and managing medical advice. The "long haul" theme captured unexpected problems and complications, quality of life, need for resources, provider burnout, and balancing hope with realistic expectations. Information seeking emerged as a distinct theme. One has to conceptualize an ongoing feedback loop as family caregivers appraise care demands and resources, and the factors that affect caregiver stress response. The experience in Armed Forces illness suggests that caregivers of all neurotrauma patients ought to be

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fully informed about the various aspects of their disease and treatment and, in increasing numbers, they assume a proactive role in their own care. Sometimes there may be high levels of dissatisfaction among patients and their relatives with the information they receive after a head or spine injury. Because information needs are emergent along with the condition of the patient, patients and caregivers are not likely to know all of their information needs during the acute phase. Neurosurgeons and critical care specialists may not be ready to support patients with the range of quality health care information that caregivers might need on care of a vegetative patient, pain management, quality-of-life assistance, family problems, psychosocial issues, home care, managed care, and complementary and alternative medicine. A growing body of research finds that when patients and families have a better understanding of their diagnosis and treatment, they are more able to cope with their illness (e.g., adjust to stressful situations and overcome problems), use the health system more effectively, and have less psychological distress². Improved coping strategies, in turn, generally result in better adjustment to a realization of final outcome. Research is lacking, however, to explain how best to achieve this understanding for patients and their families³. Health education theory suggests that just because information is available does not mean that it is in a format that will be useful. An understanding of how people seek, use, and process information can help health practitioners structure and deliver information more effectively⁴. In patients with neurotrauma, the education of patients and their family caregivers, the chronic illness management model of Corbin and Strauss⁵ as a conceptual framework to understand how information needs change, is quite useful (Table 1). This theory makes a distinction between the “course of illness” (a medical perspective) and illness trajectory (a sociological perspective that reflects the physiological unfolding of a disease). The diagnostic period that accompanies chronic illness is conceptualized as a “diagnostic quest,” with phases that include uncovering the source of symptoms, the announcement, and the postdiagnostic or “filling-in” period. Management of chronic illness after diagnosis — the process of “accommodation” — encompasses the day-to-day struggle of patients and families as they try to keep some sense of balance and give meaning to their lives. Central to this theory is the fact that patients and their families, not the medical staff, are the key players in accommodating a chronic illness at home. Family caregivers were purposively selected to address needs across the trajectory of the disease.

Hence, what is required is, (1) improving the delivery

Table 1 : Clinical trajectory coding scheme following neurotrauma (adapted from Corbin & Strauss⁵, and Rolland)⁶

Phase	Stage	Description
Crisis	Diagnostic	
	quest	Acute phase
	Comeback	Journey back to a workable life within the boundaries imposed by physical and mental limitations — may be partial or complete, depending on the injury
Chronic	Stable	Symptoms may still be intrusive; regimens still difficult; long-term management and physical wear and tear; a time of adapting (to devices and routines)
	Unstable	Symptoms (new or prior) occur such as hydrocephalus, sepsis, failure of spinal implant; additional treatment may be required; patient may or may not return to a stable condition
	Deteriorating	Treatment is not effective or not possible as in PVS; the patient loses functional (physical and/or cognitive) ability, develops pressure sores.
Terminal	Dying	Due to sepsis, pulmonary complications, etc. The last weeks of life; hospice home care generally sought; patient and family prepare for death

of information; this part is helped by the information available on the internet. This at times may however raise unrealistic expectations, like the role and availability of stem cell therapy, the gullible placing faith in the unscrupulous (2) enhancing communication among patients, families, and health care providers; and (3) providing psychosocial support for family caregivers.

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