

## Traumatic Brain Injury: Caregivers' Problems and Needs

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### ABSTRACT

Traumatic brain injury (TBI) is an increasingly major world health problem. This short review using the most pertinent articles on TBI caregiving problems and needs highlights the pressing issues. Articles focusing on both TBI-caregivers' problems and needs are rarely found, especially for developing countries. Most TBI-caregiving is done by family members, whose altered lives portend burden and stresses which add to the overwhelming demand of caring for the TBI-survivor. Lack of information, financial inadequacy, anxiety, distress, coping deficits, poor adaptability, inadequate knowledge and skills, and a poor support system comprise the major problems. Dysfunctional communication between caregivers and care-receivers has been little researched. The major needs are focused on health and rehabilitation information, financial advice and assistance, emotional and social support, and positive psychological encouragement. In time, health information needs may be met, but not emotional support. Information on TBI caregiving problems and unmet needs is critical to all relevant healthcare stakeholders.

**Keywords:** caregivers, rehabilitation, traumatic brain injury

### INTRODUCTION

Traumatic brain injury (TBI) is an increasingly major health problem worldwide. It is widely acknowledged that TBI has substantial impacts on both patients and their families. The people with TBI often lose their functional ability and independent living. Consequently, most TBI patients rely on their families to provide care and support, hence the emerging roles of care-receiving and caregiving respectively. Families then confront numerous challenges and stresses. They need to take care for a person who is different from his/her previous self before the injury. Thus, caregiving for TBI patients is overwhelmingly burdensome and exhausting.

### Caregivers' problems

Caregivers find TBI-caregiving a burden, although some of them express satisfaction which outweighs the disadvantages. Indeed, caregivers experience a range of problems such as anxiety, depression, as well as financial and other practical difficulties.<sup>1</sup>

In the majority of the cases, since families comprise the primary TBI-caregivers, some studies on family caregiving experience have been conducted, especially in the West. Caregivers complained of a lack of pertinent information and resources especially on the particular care-receivers' condition, treatment, and prognosis.<sup>2</sup> Explanations provided by healthcare professionals are often inadequate to understand the

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injuries, their sequelae and consequences. During the earlier phase of the post-injury period, such inadequacy causes distress. Subsequently, in the later phases, family life and functioning may become disruptive due to difficulty in adapting and adjusting to a transformed living style. Many problems are unanticipated and management strategies have not yet been established. It is found that most family caregivers are unprepared and inexperienced in caregiving. Caregivers may not understand the rationale of treatments, caring strategies, and possible behaviour changes of TBI-patient. Lack of specific information about TBI especially on financial and resources planning, and on optimal caring for the care-receivers and caregivers, contributed to family psychological distress.<sup>3</sup> Usually the caring component also includes rehabilitation strategies and practice. These necessities add more burden to the overwhelmed caregivers.

Behavioural and personality changes following TBI may devastate a caregiving family's functioning. The families' struggle to manage the behaviour of TBI-patients may become a primary determinant of family burden. Inadequate preparation of caregivers and patients to deal with the subsequent personality and behavioural changes is a major complaint. Family members may lack the skills to manage, cope, and provide care in TBI-rehabilitation. Such negative experiences increase stress. Consequently, psychological problems in caregivers following TBI are common.<sup>2,4</sup> They experience continual strains and depression. These emotional problems may persist and in some cases led to increased stress, hence resulting in distress symptoms.

It is suggested that the prolonged distress predicted poor health of caregivers.<sup>5</sup> Some caregivers are also at a risk for getting communicable diseases. Moreover, regular caregiving role with demands of daily activities may cause muscle strain, skeletal injury, arthritis and other physical discomfort and pain. Altered patterns of exercise, diet, and a substantially-burdened life predict poor emotional and physical health. The differential impact of caregiving on diverse age groups has not been well researched. This area deserves more attention due to the changing demography of world population with an increasing longevity.

Many caregivers face financial hardships.<sup>2</sup> The long-term recovery and rehabilitation incur substantial direct and indirect costs of treatment. Additional expenditure is required to purchase rehabilitation-aid items and life-adaptive devices. Many parents take time-off work to accompany their child in hospital or for caregiving after discharge. Hence families lose income because of TBI patients at home. Usually one parent gives-up his/her job to care for the TBI-survivor. Furthermore, additional transport costs also burden the family. Travelling costs may escalate due to hospital visits, therapy sessions, and patronized school transport for a TBI schooling-

child.

Spiritual coping influences the caregiver's wellbeing, especially psychological distress. Caregivers who use a religious or spiritual belief's coping strategies experience lower levels of depression. Association of spiritual belief and the caregiver's health has not been fully examined, although some studies have recently been conducted on cancer caregiving correlates.<sup>6</sup> It is important to include religious and spiritual belief in understanding and evaluating caregiver distress, adaptation and adjustment.

Family members caring for TBI-survivors indicated the existence of communication breakdown between caregivers and care-receivers, which led to a declining quality of their interaction and relationship. Caregivers face the challenge of maintaining relationships with persons who are physically present but may not be able to meaningfully engage in social or verbal exchanges. Impaired communication may structure and reflect family dysfunction. Family members are usually reluctant to express their negative feelings. This is especially so due to cultural constraints in many developing countries. Caregivers hide feelings of annoyance, resentment, blame or grief. Nevertheless, some do express anger and aggression. Thus, caregivers need professional assistance to understand and improve family communication.<sup>5</sup>

#### Caregivers' needs

In developed countries, needs of family members with TBI-survivors have been well studied. The literature has identified many critical family needs, the major ones being health and rehabilitation information, financial advice and assistance, and emotional and social support.

The need for psychological support, maintaining hope and the opportunity to discuss feelings also ranked as important. In order to provide care for their injured relatives, family members also reiterate a need for professional direction, support and respect.

Family needs change over time as care settings, functioning, and personal roles change. Recent studies of family needs focused on the evolution of needs over time. Rotondi et al.<sup>7</sup> identified caregiver needs via multiple phases: acute-care, in-patient rehabilitation, return-home and long-term living in the community. Prominent themes during in-patient phases include provider quality, emotional support, and understanding the injuries. During the latter two phases, the major family needs included guidance, life planning, community integration, and behavioural and emotional issues.

In the acute phase of post-injury, family members spend most of their time in the intensive care unit or acute

rehabilitation unit in a hospital. Families then express the need for information about the injured patient's condition, prognosis and expectations. They also want to fully understand the medical care that is needed by the patients. Caregivers also sought better understanding of the long-term changes and implications of the injuries including the process of rehabilitation and restitution.<sup>8</sup> Hence, the family care giving-members would gain by being trained with skills to cope with the impairments, deficits, and sequelae of TBI.<sup>8</sup>

After discharge, family members emphasized the need to obtain continual reassessments of the TBI-survivor to measure rehabilitation progress. For advice and guidance, caregivers sought to communicate with health professionals to answer the health/medical questions and to solicit various support and encouragement. Caregivers need help in creating an enthusiastic and positive environment for their TBI patients.

In the later post-injury phase, some families reported health information needs as being met, but not emotional support, instrumental support, and professional support needs. Support needs are needed mostly from other family members and friends and similar-interest groups to share experiences and respite services. Social/community support groups are sought for various professional and non-professional assistances. This service is crucial to help a family cope with the sequelae of TBI and in preventing ensuing emotional problems. Families may also require referral to the appropriate legal assistance agency to deal with insurance claims and other legal issues. Families also may require help in identifying possible sources of financial help such as charities, religious organizations and foundations.<sup>8</sup>

The development of instruments to measure family needs has led to a better understanding of met and

unmet needs of family caregivers. The Family Needs Questionnaire (FNQ) consists of 40 items which comprise six categories: health information, emotional support, instrumental support, professional support, community support network, and involvement with care.<sup>9</sup> The FNQ has been widely used to highlight specific aspects of family needs and their relationship to various characteristics of families and TBI-individuals.

Recently, researchers from Colombia<sup>10</sup> used the FNQ and assessed the need of 29 TBI-caregiver families. The most important needs included health information, community support network, and professional help and advocacy. These are typical of the critical needs of caregivers in developing countries. Communication with professionals is thus sought for advice or service, to have questions answered honestly and to elicit explanations in understandable terms.

## CONCLUSIONS

The sequelae of TBI have a significant impact on caregiving-family members. Caregivers face numerous overwhelming challenges in the caregiving process. The needs of caregivers are complex and change with time. In order to improve the quality of life and health outcomes for TBI patients and their families, the required services, supports, and dimensions of care need to be identified. Understanding of caregivers' problems and needs will help to better inform nursing and health authorities, and all relevant healthcare stakeholders, of necessary assistance to TBI-caregivers. Community nurses, for example, are better prepared to inform caregiving-families of benefits and resources. Caregiving researchers and policy-designers too will be able to plan for appropriate interventions to meet caregiving-families' needs.

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