

Guest Editorial

International Perspectives on Caregiving

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Every year, millions of people around the world suffer spinal cord injuries, traumatic brain injuries, and strokes. Spinal cord injury (SCI) often strikes young and healthy individuals and is estimated to affect between 11.5 and 57.8 individuals per million around the world, causing death, paralysis, and serious secondary medical complications [1]. Costs associated with SCI have been estimated at over \$1 m per patient, including those associated with home modifications, supplies, nursing, and home care [12]. Like SCI, traumatic brain injury (TBI) is a leading global cause of death and disability in the young, estimated to affect roughly 10 million people around the world each year [6,7]. The costs of TBI are many, including those related to direct hospitalization and rehabilitation, lost earnings, and reduced quality of life [5]. Strokes are the third most common cause of death in developed countries around the world; an estimated 15 million people suffer strokes each year, and roughly 5.5 million of these die [10]. The economic burden of strokes is great: the American Heart Association estimates that \$73.7b will be spent on treatment of stroke victims in 2010 alone, and strokes are a major cause of long-term serious disability [2].

Overall, persons with debilitating conditions like TBI, SCI, and strokes often require the services of short- and long-term care [3,8,14]. In general, family members often take on the role of caregiving which requires significant amounts of time and dedication,

and usually results in high levels of physical problems, stress, and burden [9,11,13]. Additionally, caregiving often creates high costs for both caregivers and society [4].

Regardless of one's country or culture, being a caregiver of an individual with a chronic condition is a stressful experience that is associated with an increased risk of physical, emotional, and/or financial difficulties. Despite the increased availability of effective caregiver and family interventions available to unpaid caregivers of individuals with TBI, SCI, and stroke, additional research of the impact of caregiving on these patients is warranted. Even less is known about the experiences and influence of family caregivers from countries other than the United States. This special issue of *NeuroRehabilitation* offers insight into understanding the role and contributions of unpaid caregivers on two continents representing four countries: the U.S., Canada, Australia, and Colombia. The majority of the articles in this issue are focused on caregivers of individuals with TBI. Most articles examine caregiver needs, psychosocial functioning (including social support, burden, coping, quality of life, and life satisfaction), and intervention effectiveness. Short summaries of the articles are described below.

The first article by Gan and colleagues studied acquired brain injury (ABI) caregiver support needs through data triangulation from multiple interview sources across different settings. Thirty-nine caregivers across urban and rural settings in Ontario, Canada participated in focus groups that focused on ABI support services received, their utility, access barriers, needed supports, and suggestions for service delivery. The results indicated that caregiver support needs transcend geographical boundaries and must be comprehensive,

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accessible, long-term, and encompass education, emotional, and instrumental support.

Kreutzer and colleagues described and compared caregivers' and patients' helpfulness and goal attainment ratings of the Brain Injury Family Intervention (BIFI), and qualitatively evaluated their perceptions of most important things learned. Seventy-six caregivers and 76 patients with ABI in Virginia, USA participated in the BIFI, a structured family intervention program which includes educational, skill building, and psychological support components. They found that session helpfulness ratings for caregivers and patients were uniformly high as were ratings of the extent to which session goals were met. Between group comparisons did not indicate differences for individual session helpfulness or goal attainment ratings. Qualitative analysis of most important things learned provided corroboratory evidence that BIFI topics were relevant and consistent with program goals.

Butera-Prinzi and colleagues aimed to restore the lack of peer support programs for individuals with an ABI and family members in Australia by use of the Family To Family Link Up Program (f2f Link Up), a pilot program aimed to promote connections between families who have a family member with an ABI. Results indicated that the program had positive impacts for both families and facilitators. Useful feedback on program implementation issues, as well as benefits and constraints of the program are described.

Chronister and colleagues studied the degree to which stress-coping variables contribute to quality of life (QOL) among caregivers of individuals with predominantly severe traumatic brain injury (TBI) in California, USA by examining the direct effects of functional competency, caregiving appraisal, coping, perceived social support, and family needs on QOL. Results showed that the full model accounted for 68% of the variance in QOL; caregiving appraisal, perceived social support and family needs remained significant after controlling for other stress-coping variables; and of these sets, emotional social support, social needs, and perceived burden were the significant individual predictors. Emotional social support and social needs mediated the relationship between perceived burden and QOL.

Wade and colleagues prospectively examined differences in maternal and paternal response to early childhood TBI over time relative to a comparison cohort of mothers and fathers of children with orthopedic injuries (OI) in Ohio, USA. Results showed that fathers were more likely than mothers to use denial to cope

following moderate and severe TBI, but not OI. Conversely, mothers were more likely to prefer acceptance and emotion-focused strategies than fathers regardless of the type of injury. Additionally, fathers reported greater injury-related stress and distress than mothers over time, with pronounced differences in the severe TBI and OI groups.

Livingston and colleagues examined the predictors of family caregiver life satisfaction at one and two years after traumatic brain injury (TBI). A prospective collaborative longitudinal study was used to assess 336 family members caring for individuals with TBI from the TBI Model Systems database (USA). Compared to normative data, family members of individuals with TBI experience reduced life satisfaction in the first 2 years following TBI. Psychiatric and neurobehavioral problems, such as drug use and depression, as well as motor dysfunction in survivors may be important contributors to decreased life satisfaction among their caregivers.

Arango-Lasprilla and colleagues studied a group of thirty-seven family caregivers of individuals with SCI in Neiva, Colombia in order to assess family needs, caregivers' psychosocial functioning, and the relationship between these two variables. Information, economic, emotional, community support, and respite needs were most frequently reported among this group of Colombian caregivers. They found that approximately half of the sample reported some level of burden, depression, or being dissatisfied with life. Psychosocial functioning was related to various family needs.

Clark and colleagues investigated the contribution of caregivers' characteristics to adherence to follow-up appointments by minority persons with first episode stroke in Texas, USA. Of 61 primary caregivers of minority persons, there was no difference in appointments attended based on race/ethnicity. Hispanic caregivers reported a greater belief that powerful others exerted control over their health on the External Control by Powerful Others subscale of the Multidimensional Health Locus of Control Scale (MHLC). There was also a trend for Hispanics to score higher on the External Control by Chance subscale of the MHLC. Individuals with stroke were less likely to attend appointments if their caregiver believed that health was related to chance factors.

Ramkumar and Elliott reviewed current practices in providing caregiver support, outlined considerations for developing collaborative interventions, and made recommendations for assessing intervention effectiveness consistent with the nature of the adjustment pro-

cesses among caregivers and care recipients. Because family caregivers of individuals with neurotrauma function as *de facto* extensions of the health care system, their challenges may result in negative consequences for their own physical and mental health, which then impacts the well-being of their care-recipient.

In conclusion, caregivers play an important role in the recovery of patients with neurological trauma. From an international perspective, this special issue of *NeuroRehabilitation* addresses a number of important topics related to caregiving. Still, more clinical research is required to better understand the reactions and needs of caregivers so we can develop programs that most effectively help people return to more normal lives.

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