



1st World Congress on Healthy Ageing, Kuala Lumpur, Malaysia

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Caregiving-Rehabilitating Traumatic Brain Injury: Elderly Caregivers' Challenges

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Keywords: Caregiving-rehabilitation, traumatic brain injury, elderly caregivers

Background; Caregiving (CG) is an overwhelming challenge and long-term caring for people (care-receiver (CR)) with traumatic brain injury (TBI) is mainly provided by family members. The cognitive deficits, physical impairment, communication deficit, and psychosocial, spiritual and emotional fluctuations following TBI, challenge a family system.

Method; Nine-year records and analyses on caregiving and rehabilitation of an adult-son (first and second authors) augment literature findings.

Result/Observation; Elderly CG suffers from distress and anxiety, and decreasing motivation due to the perceived decreasing CR recovery. It is difficult to manage the CR behavioural problems, to access appropriate rehabilitation services, and to continually implement home-based rehabilitation.

There are indications that spiritual resilience do improve CG's and CR's well-being, in adapting and adjusting to the caregiving challenges. Elderly CG faces memory deterioration leading to inadvertent neglect of medication and rehabilitation of the CR. In time, the CG's health and wellbeing decreases hence less able to fulfil their domestic and job responsibilities.

Financial difficulty is a central issue. Pensions and savings are insufficient to cover living costs and to sustain TBI treatment, medication, and rehabilitation services. Moreover, in Malaysia, there is little local information and available resources and support system dealing with TBI. Learning to use alternative and augmentative communication method is an added burden.

Conclusion; CG "Burnt-out" is common. Formation of relevant support groups is imperative. Education and training of parents and of support groups are warranted. Caregivers' networking system should be instituted. Awareness and compassion programmes are needed for health professionals and the general public.