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The perceptions of community integration one year post rehabilitation for survivors of traumatic brain injury and their significant others: a South African perspective

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Abstract

Background**:** Traumatic Brain Injury (TBI) is a serious public health problem worldwide. It is a major cause of death among younger adults and is a leading cause of lifelong disability in persons who survive it. There are a large number of young adults living with life-long disabilities as a result of traumatic brain injury worldwide, with higher numbers existing in South Africa. Whilst previous research internationally has examined issues of community integration and difficulties experienced by persons with traumatic brain injury and their significant others or caregivers, a paucity of research of this nature exists in South Africa. This study intended to explore whether a gap in clinical practice exists with regard to aspects of intervention and support, underpinned by an ambiguous definition of community integration for survivors of traumatic brain injury and their significant others

Method: The main aim of the study was to explore existing feelings of community integration and active participation in patients with traumatic brain injury who have been discharged from rehabilitation services in private practice in Johannesburg, South Africa. In this study, the sample comprised of 10 survivors of TBI and 10 significant others (SOs). The objectives were to describe and compare participants and significant others' or caregivers experience of community integration and factors that influenced the perceptions by each (i.e. the patient and the caregiver) as well as to document barriers and facilitators to community integration and active participation within the, familial, social and work context. Lastly the study aimed to determine if the qualitative analysis of formal assessment measures (FIM and CIQ-R) match perceptions of persons with TBI with regard to Community Integration (Landrum et al., 1995).

Results: Across various areas of comparison, participants who scored higher in the CIQ-Rand FIM measures, often expressed more subtle difficulties or challenges that landed up going undetected and ultimately contributed to their personal feelings of poorer community integration. Various studies, including the current study reveal that significant others have many unmet needs in terms of what they know and what they should expect with regard to handling their loved one with a TBI.

Implications: This research has highlighted the fact that our South African context is lacking with regard to ongoing management of individuals surviving TBI, with reduced funding available for outpatient therapies, a lack of post discharge programmes and a general lack of education and information given to family members of TBI survivors upon discharge. As such this should be a major focus of health care providers in the future. This research revealed many subtleties that impact perceptions of community integration but go undetected by formal measures. Such subtleties could be used to direct specialised programmes, which should be made available to TBI survivors post discharge from rehabilitation services.

Keywords: traumatic brain injury; community integration; rehabilitation; functional outcomes; private practice, developing countries, community resources, south Africa