

# Community integration after severe traumatic brain injury in adults

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## Purpose of review

Despite being the main cause of death and disability in young adults, traumatic brain injury (TBI) is a rather neglected epidemic. Community integration of persons with TBI was, until recently, insufficiently informed by clinical research.

## Recent findings

To bridge the gap between rehabilitation and community re-entry, the first task is to assess the person, using TBI-specific outcome measures. The second task is to provide re-entry programs, the effectiveness of which is assessed by those measures, using well designed studies. There are very few such studies. However, there are some effective comprehensive programs and others which are specifically targeted dealing mainly with return to work, behavior, and family issues. The complex psychological and environmental components of the disability require individualized and often long-term care.

## Summary

For persons with severe TBI trying to achieve the best possible community integration a new semiology is required, not just limited to medical care, but also involving social and psychological care that is tailored to the needs of each individual and family, living within his/her environment. Currently, only a minority benefit from well validated programs.

## Keywords

community integration, health-related quality of life, long-term outcome, rehabilitation programs, traumatic brain injury

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## Introduction

Traumatic brain injury (TBI) is a major cause of death and of disability, particularly in persons under 40 years of age. There are around 6.2 million Europeans with TBI-related disability. However, TBI is in many ways a 'silent epidemic', particularly for the so-called 'chronic phase'. The long-term physical and, moreover, cognitive/emotional impairments and the resulting limitations of daily-life activities affect the person's self-image, coping strategies, and community reintegration [1].

Bridging the gap between medical care/rehabilitation and community integration means changing semiology from a medical-oriented healthcare perspective to a more psychological and social perspective. Community integration has been defined by three main areas: employment, independent living, and social activity.

The purpose of this study is to review recent advances in the field of community integration after severe TBI in adults. A literature search was performed in PubMed and PsycInfo.

Two major issues emerged: diagnosis, evaluation, outcome measures; and targeted and holistic programs addressing community integration.

## Assessment of community integration and quality of life: validated outcome measures and predictive factors

Malec [2\*\*] identified methodological and ethical issues in TBI clinical research. The goal of evidence-based medicine (EBM) is to develop a scientific basis for choosing interventions that will benefit individuals with defined characteristics. The randomized controlled trial (RCT) is the gold standard for EBM methodology. Interventions in TBI rehabilitation may be appropriately studied within a social model of disability. Ethical practice requires not only scientific evidence for an intervention, but also best practices recommended by professional traditions and consensus, and the individual's known needs and evolving situation [3,4].

## Outcome measures

The integrated biopsychosocial approach represents a significant challenge for the evaluation and development

of TBI re-entry programs. Their assessment needs validated scales which are specific to the chronic phase, and commonly used in TBI. Examples are the Community Integration Questionnaire (CIQ) [5], the Mayo-Portland Adaptability Inventory (MPAI-4) [6], the Glasgow Outcome Scale Extended (GOSE) [7], and the European Brain Injury Society (EBIS) document [8]. In addition, the International Classification of Functioning, Disability, and Health (ICF) [9] offers a taxonomic tool for conceptualizing and codifying symptoms and barriers to community participation, and allocating resources.

Increasingly, outcome assessment incorporates the subjective opinion of the person with TBI and of his/her family. Self-awareness may be assessed by the Patient Competency Rating Scale (PCRS) [10<sup>••</sup>], mood and behavior by the Hospital Anxiety and Depression Scale (HADS) [11]. The ultimate goal of community integration is health-related quality of life (HRQOL), and the unique TBI-specific HRQOL scale, QOLIBRI, has now been validated in six languages [12<sup>•</sup>].

The most widely used approach to evaluating TBI-specific programs aimed at community reintegration is the accreditation process of The Commission on Accreditation of Rehabilitation Facilities (CARF). CARF is a nonprofit American/Canadian organization which has assessed more than 500 programs in North America and in Europe [13].

#### **Predictive factors of community integration**

Older age at injury, years after injury [14<sup>•</sup>,15<sup>••</sup>,16<sup>••</sup>], dynamic assessment of learning ability [17], coma length, Barthel Index score, hospital discharge destination, and preinjury community integration [18<sup>•</sup>] are usually reported as the major determinants of postinjury community integration.

As emphasized by Ben-Yishay and Daniels-Zide [19], and Prigatano [20], psychosocial variables play a crucial role, namely, motivation (a desire for, and personal engagement with rehabilitation); sufficient awareness and acceptance of the handicapping consequences of TBI; sufficient emotional stabilization; and social and family environment, particularly a supportive partner and identified and committed professionals.

The five best predictors of HRQOL (measured by QOLIBRI) in the community integration period are depression, amount of help needed, health complaints, anxiety, and GOSE score [12<sup>•</sup>].

#### **Community integration targeted programs**

Although the major part of motor and cognitive recovery takes place during the first year, persons with severe TBI can improve after injury for many years [21<sup>•</sup>].

#### **Key points**

- Use validated and TBI-specific measures of community integration and HRQOL.
- When elaborating program studies, participant characteristics and program content have to be specified.
- Promote best practice in research, including RCT, single-case experimental design, and consensus conferences.
- Long-term follow-up and quality assurance are needed, and an individualized and evolving approach based on individual needs, hopes and life situation.
- Promote community-based, holistic and multidisciplinary programs, with continuity of care and TBI-specific networks.

Targeted programs aiming at improving various physical, cognitive and behavioural impairments may increase patient independence.

#### **Physical therapy interventions**

Physical disability, in severe TBI, can be a major obstacle to community integration. The physician has a pivotal role here by coordinating other health professionals. He/she is confronted with a range of problems, such as epilepsy, hydrocephalus, hormone deficiency, sensory impairments, oro-pharyngeal and bladder/bowel dysfunction, movement and balance disorders, spasticity, orthopedic issues, pain, and frequent comorbidities in those vulnerable patients. Recovering mobility is a main challenge. It often requires long-term rehabilitative maintenance, and may involve a wheelchair, and assistive devices, for facilitating independent functioning in the community [22].

#### **Neuropsychological rehabilitation**

Various specific neuropsychological rehabilitation programs, focused on divided attention [23<sup>•</sup>], metacognitive skills training [24] or self-awareness [25] can improve the targeted skill, but with little transfer to nontrained skills or independence in everyday life. This is a recurring problem in neuropsychological rehabilitation in the chronic phase [26<sup>••</sup>].

Wilson *et al.* [26<sup>••</sup>] demonstrated the efficiency of electronic devices to compensate memory deficits. For Culley and Evans [27], mobile phone and text messages use improved memorization of rehabilitation goals. Information provision on TBI programs is increasingly web-based [28].

#### **Behavioral and emotional dysfunction, the major predictor of low community integration and poor HRQOL**

Two literature reviews [29<sup>•</sup>,30<sup>••</sup>] reported very few studies meeting level I requirements. Cognitive/behavior

therapy and comprehensive holistic re-entry programs improve behavioral problems. Serotonergic antidepressants are the best option for depression. Methylphenidate [31<sup>•</sup>] and rivastigmine [32] improve information processing in some persons with TBI. Antipsychotic drugs should be used with caution for aggression, and adverse effects are increased after TBI [33<sup>•</sup>].

Traumatic brain injury limitations on communication, insight, and self-awareness are an obstacle to insight-based psychotherapies. Cognitive/behavior therapy and family therapy are increasingly used. Therapy may address existential issues such as mourning the loss of the preinjury hopes and aspirations [29<sup>•</sup>,30<sup>••</sup>].

Alcohol and drug addictions are frequent and have a deleterious effect in TBI. Surprisingly, many physicians fail to screen for substance abuse. Furthermore, West *et al.* [34<sup>•</sup>] showed that 40% of those who diagnosed substance abuse failed to refer such patients for treatment. In a RCT, Ponsford *et al.* [35<sup>•</sup>] demonstrated the positive effect of motivational interviewing, together with an information booklet on reducing alcohol consumption.

#### **Return to work**

Return to work (RTW) is one of the main challenges following severe TBI [12<sup>•</sup>,36,37<sup>•</sup>,38<sup>••</sup>]. The most significant predictors of a successful RTW are better marital and pretraumatic work status, higher education level, socio-economic status, and current income, less severe injury, shorter hospitalization length, being a Caucasian, and HRQOL [12<sup>•</sup>,36,37<sup>•</sup>].

Fadyl and McPherson [38<sup>••</sup>] identified three approaches to vocational rehabilitation: work skills rehabilitation, guided work trials and assisted placement with transitional job support; individual placement model of supported employment with on-the-job coaching and unlimited intervention time and extent; and a case management model, with early intervention and continuity of care, and coordination with other rehabilitation services. The third approach was the most effective, and Fadyl *et al.* noted the importance of the therapeutic alliance with a skilled practitioner.

Wrona [39<sup>•</sup>] described the vocational rehabilitation process in the state of Washington. Forty-four per cent of persons with severe TBI received vocational rehabilitation, including 65% who returned to work or were considered as employable. Vocational rehabilitation was provided in four phases: early intervention involving employee, employer, physician and vocational counselor; assessment of ability to work; retraining plan; and plan implementation. RTW may be full or part-time, sheltered work, or volunteer activity. Ouellet *et al.* [40<sup>•</sup>] noted that the volunteer group included the most severely

injured, and those with a longer delay after injury. One key to successful RTW is the belief on the part of service providers that employability is related to the right type, level, and intensity of support when efforts are made to help people locate workplaces in which their skills will be valued and their limitations accommodated [41<sup>••</sup>].

#### **Return to driving**

Hemianopia, epilepsy, inattention, aggression, and substance abuse may all lead to inability to drive, thus impeding employability, social relationships, independence, and self-image. Severely injured patients should have a driving assessment, including neuropsychological examination, a simulator test, and an on-road driving test [42].

#### **Sport, leisure, culture, and spirituality**

Sports can be a major promoter of community integration, especially for those without severe physical damage. For the most severely injured, other nonsporting leisure activities may improve familial and social reintegration. The choice of activity is typically based on previous life experience, and the wishes and abilities of the person with TBI [43]. Better mental health is known to be associated with membership of a religious group. Positive spiritual experiences and willingness to forgive are related to better physical health [44].

#### **Veterans programs**

Traumatic brain injury veterans often sustain blast injury with sensory impairment, pain, reduced motivation, emotional dysfunction, substance abuse, and impaired family dynamics [45<sup>•</sup>]. The Assisted Living Pilot Project at the Defense and Veterans Brain Injury Center-Johnstown combines traditional services with telemedicine-teleconferencing and embedded research on outcomes and interventions [46<sup>•</sup>].

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#### **Community integration holistic programs**

A systematic review, from 1990 to 2008 (Geurtsen *et al.* [47<sup>••</sup>]), of comprehensive re-entry programs after severe acquired brain injury (ABI) yielded two RCTs, five controlled comparative studies, and six uncontrolled longitudinal cohort studies. Those studies showed a reduction in psychosocial problems, better community integration and work participation, more so for day-treatment programs than for residential programs and for neurobehavioral interventions. Overall, there were methodological limitations, due to poor description of patient samples, and intervention characteristics. The author highlighted the importance of an integrated multidisciplinary team, and found that community-based therapy is as effective as residential programs. Some programs use the goal attainment approach, which provides subjective satisfaction, motivation, a sense of partnership, and self-awareness [48].

Altman *et al.* [49\*\*] carried out a retrospective analysis of a community-based postacute brain injury rehabilitation on 489 persons with TBI, compared to 114 who were discharged early, prior to program completion. Significant differences in favor of the former were found on MPAI-4 ( $P < 0.0001$ ). Gracey *et al.* [50] propose a model of the change process in rehabilitation called the Y-shape model focused on level of participation but also on the personal meaning of this to the person with TBI.

### Case management

Case management was initially developed in the USA to facilitate cost-effective rehabilitation. In this approach, one person (the case manager) is given responsibility to formulate a plan of intervention, identify the many services likely to be needed by the brain injured person, and then help the patient navigate through the maze of services. Studies by Cope [51] demonstrated that efficient case management led to shorter inpatient rehabilitation stays, and improved rehabilitation outcomes. Case management is developing in Europe. The British Association of Brain Injury Case Managers (BABICM) has now developed a competency framework to assure quality, and help the professional development of the case manager [52\*].

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### Impact on family, caregiver stress and long-term burden

The family has two characteristics: it is caregiver and it is suffering.

#### Family

Traumatic brain injury affects the whole family. Several studies indicate persisting and significant levels of depression, anxiety, and somatic symptoms. Higher caregiver distress was associated with caring for survivors who had worse functional status, received more supervision, and used alcohol excessively [53\*].

Traumatic brain injury family associations are an important part of the service network, and provide peer groups, mutual help, and counseling. Regional associations are often grouped in a national union, which may accrue political power, and convince public authorities to pay attention to this 'silent epidemic', and to give financial support for integration programs.

#### Sex and partnership

Complaints of sexual dysfunction are related to isolation, emotional and behavioral change, and impaired communication, rather than physical/organic difficulties. Nevertheless, unsatisfied sexual desire, coupled with impulsivity, reduced empathy, and difficulty in understanding social situations can explain the (relatively

infrequent) sexual assault or aggression. The partner of the injured person, often a woman, may sustain a heavy emotional burden, related to loss of support and increased responsibilities. There is a high risk of divorce with a divorce rate of 58% five years following injury. Managing sexual issues, especially in residential facilities, is very challenging for staff, and requires patient-centred care, with a respect for emotional needs, while balancing an individual's rights and limitation of liberty necessitated by the risk of violence. For female patients pregnancy is a difficult challenge, requiring reliable contraception and/or mature decision founded on the ability of the couple to bring up children [52\*,54].

### Professional training and concerns

A well trained, experienced, open-minded, and motivated professional is a key element in a TBI re-entry program. US and European master classes and university courses with practical exercises and in-facility courses are available [52\*,55\*].

### Medico-legal aspects

Whatever the compensation system, the physician, the psychologist, and others, for example, the occupational therapist, play a major role. TBI requires a thorough assessment of cognitive/behavior sequelae, family needs, and functional consequences such as loss of employment. The complexity of TBI requires an expert experienced in TBI care, and a solicitor trained in injury compensation [51].

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### The patient and the life project

Over time, the impact of the initial severity and of the biomedical aspects decreases, whereas the impact of the psychological and social/environmental aspects increases. TBI is particularly common as a result of road traffic accidents in adolescents and young adults and comes at a time when they are making decisions about important life issues regarding independence, work and relationships. Asking patients for their subjective opinion is crucial in prioritizing therapeutic goals, taking into account their personal needs, values and hopes. It also facilitates the therapeutic alliance, thus helping the participant to build a new life, in his/her own cultural, familial, social and environmental context [12\*,55\*,56\*,57].

### Continuum of care

One critical issue is transition between early rehabilitation and community integration. At that transition, TBI persons are still often left alone with their families, without significant clinical support, leading often to psychosocial deterioration. To address this issue, a transitional program was created, in France, with four aims: evaluation, retraining, social/vocational orientation, and follow-up (UEROS). Each of the 32 UEROS comprises a

multidisciplinary team providing support for 6 months to acquired brain injuries, mainly TBI (67%), and long-term assessment and follow-up. Out of 395 ABI patients, 68% were moderately or severely disabled at admission. Two years after discharge, 33% returned to their own accommodation and 49% to some kind of work. Apart from the mandatory continuity of care all the way through, there is a need for TBI-specific networks, if possible in the same geographic area [55\*],

### Do the services meet the needs?

Lefebvre *et al.* [58] interviewed persons with TBI, families and professionals and found that services were considered to be inadequate, as follows: information, communication planning, resources coordination and coherent support, feedback in progress and issues, and access to medical records; financial protection, work adaptation and how to access care in psychological crises; recognition of the need for family and caregiver training and support, peer groups and associations; and continuity of care, awareness and access to TBI-specific programs.

### Conclusion

For persons with severe TBI trying to achieve the best possible community integration a new semiology is required, not just limited to medical care, but also involving social and psychological care that is tailored to the needs of each individual and family living within his/her environment [18\*]. Community-based holistic, interdisciplinary, and TBI-specific programs are needed, and outcomes must be rigorously assessed by effective measures. There are currently too few services to meet the needs of all those who have suffered a TBI, especially in the long term [53\*].

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### References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (pp. 711–713).

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This study represents an outstanding contribution to the place of evidence-based medicine and randomized controlled studies in TBI. However, in the absence of strong evidence, the ethical practice of brain injury rehabilitation also requires an awareness of current best practices recommended by professional traditions and consensus in individual care. He insists on the social/environmental aspects of disability when targeting the interventions.

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- 49** Altman IM, Swick S, Parrott D, Malec JF. Effectiveness of community-based rehabilitation after traumatic brain injury for 489 program completers compared to those precipitously discharged. *Brain Impair* 2010; 11:199.  
This retrospective study grouped seven centers and 489 persons with TBI with a control group. At 12-month follow-up, program completers had a higher score for the full MPAI-4, the Abilities, Adjustment, and Participation indexes (all scores at  $P < 0.0001$ ).
- 50** Gracey F, Evans J, Malley D. Capturing process and outcome in complex rehabilitation interventions: a 'Y-shape' model. *Neuropsychol Rehabil* 2009; 19:867–890.
- 51** Cope ND. Managing the impossible: getting better results in returning catastrophically injured people to work. *J Workers Compensation* 2009; 18:17–30.
- 52** British Association of Brain Injury Case Managers (BABICM) Competency Framework for Brain Injury Case Managers. 2010. [www.babicm.org](http://www.babicm.org)  
Despite the heterogeneity of the population served which explains the difficulty of assessing its effectiveness, case management is developing and integrates, under the leadership of the case manager, all the interventions needed by one person with TBI.

- 53** Kreutzer JS, Rapport LJ, Marwitz JH, *et al.* Caregivers' well being after traumatic brain injury: a multicenter prospective investigation. *Arch Phys Med Rehabil* 2009; 90:939–946.

Depression, anxiety, and somatic symptoms are common among caregivers. Findings substantiate the importance of clinical care systems addressing the needs of caregivers in the long term as well as survivors.

- 54** Johnson C, Knight C, Alderman N. Challenges associated with the definition and assessment of inappropriate sexual behaviour amongst individuals with an acquired neurological impairment. *Brain Injury* 2006; 20:687–693.

- 55** Truelle J, von Wild K, Onillon M, Montreuil M. Social reintegration of traumatic brain injured: the French experience. *Asian J Neurosurg* 2010; 5:24–31.

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- 56** O'Callaghan AM, McAllister L, Wilson L. Sixteen years on: has quality of care for rural and noncompensable traumatic brain injury clients improved? *Aust J Rural Health* 2009; 17:119–123.

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- 57** Weed R, Berens D. Life care planning after traumatic brain injury. In: Zasler N, Katz D, Zafonte R, editors. *Brain injury medicine*. New York: Demos Medical Publishing; 2007. pp. 1223–1240.

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