

Clinical Practice Guidelines for the Care of People Living with Traumatic Brain Injury in the Community

Summary of Key Points

Prepared by:
Dr Lyndal Trevena, Associate Professor Ian Cameron and Ms Mamta Porwal



The University of Sydney



The University of Sydney

Clinical Practice Guidelines for the Care of People Living with Traumatic Brain Injury in the Community

Summary of Key Points

Prepared by: Dr Lyndal Trevena, Associate Professor Ian Cameron and Ms Mamta Porwal
October 2004

Dr Lyndal Trevena Lecturer,
School of Public Health Room 322,
Edward Ford Building (A27)
The University of Sydney NSW 2006
Ph: +61 2 9351 7788
Fax: +61 2 9351 5049
Email: lyndalt@health.usyd.edu.au

We would like to thank those who contributed to the development of these guidelines. In particular, we are grateful for the time and commitment of the steering committee members and their supporting agencies.

- > Dr Clayton King (Royal Rehabilitation Centre Sydney)
- > Dr Louise Gardiner (General Practice)
- > Dr Kathleen McCarthy (Westmead Hospital)
- > Ms Libby Cavenagh (Northern Sydney Division of General Practice)
- > Ms Louise Mors (Hornsby Kuring-gai Ryde Division of General Practice)
- > Ms Suzanne Lulham (Motor Accidents Authority)



**MOTOR ACCIDENTS
AUTHORITY**

Funded by the Motor Accidents Authority of NSW

Contents

About these Guidelines	02
General Background Traumatic Brain Injury (TBI)	03
Common Health Issues in TBI	04
Seizures	
Somatic Complaints	
Post-concussion Syndrome	
Mental Health Care in TBI	07
Depression	
Anxiety	
Schizophrenia	
Cognitive and Behavioral Problems in TBI Patients	10
Cognitive Impairment	
Personality and Behaviour Changes	
Lifestyle Issues and Quality of Life	12
Common Lifestyle Consequences and Quality of Life to TBI Patients	
Functional Status Daily Living and Return to Work after TBI	
Issues for Carers, Friends, and Family of TBI	
Substance Abuse	15

About these Guidelines

This small summary booklet is designed to be a quick reference source summarizing the best available evidence about the longer term care of patients with traumatic brain injury (TBI). The more comprehensive version of these guidelines should be used if you want to read more about a specific aspect of TBI. The larger book describes the best available evidence more fully, lists the reference sources, suggests resources for patients and carers, gives a technical report on the guideline development and provides copies of some of the diagnostic checklists that are valid for TBI patients.

Next to the key points in this booklet we have listed the strength of evidence using the following NHMRC criteria (descending order):

- Level I = Systematic review of all randomised controlled trial
- Level II = At least one properly-designed randomised controlled trial
- Level III-1 = Well designed pseudo-randomised trials
- Level III-2 = Comparative studies with concurrent controls and allocation not randomised (e.g. cohort studies, case-control studies or interrupted time series with a control group)
- Level III-3 = Comparative studies with an historical control
- Level IV = Case series or before and after studies.

Where checklists are available in the larger version of these guidelines, this is denoted by a (*).

The evidence for treatment in TBI patients is listed as either ‘effective’, ‘insufficient/conflicting’ or ‘evidence of no effect’.

The evidence has been grouped under five broader categories – common health problems in TBI patients, mental healthcare in TBI patients, cognitive and behavioural problems in TBI patients, lifestyle issues and quality of life and substance abuse in TBI patients.

General Background Traumatic Brain Injury (TBI)

FREQUENCY

The incidence of traumatic brain injury resulting in hospitalisation in NSW each year is approximately 126:100,000. It is most common in the age group of 15-35 years and in males.

DIAGNOSIS

Cognitive and behavioural changes, difficulties maintaining personal relationships and coping with work are reported by survivors as more disabling than any residual physical deficits.

TREATMENT

Retraining and re-skilling, behavioural management, drug therapy and rehabilitation are the most common modes of treatment in patients with traumatic brain injury.

PROGNOSIS

Severe TBI is not curable and healthcare may not ultimately be able to provide the improvement desired by the patient and his or her family. General practitioners play a central role in the management of TBI patients.

Common Health Issues in TBI

1 Seizures

FREQUENCY

Late seizures are more common than early (i.e. within 7 days of injury) following TBI (10% vs. 4%) (Level III-2).

DIAGNOSIS

Late post-traumatic seizures are more likely if there are early seizures, brain contusions, CT abnormalities, focal EEGs and severe level of injury (Level III-2).

TREATMENT

Evidence of Effectiveness

Phenytoin reduces the chance of early posttraumatic seizures (Level I) RR= 0.34 (95%CI 0.21 – 0.54).

Insufficient/Conflicting Evidence

There is insufficient evidence for the effect of yoga, EEG biofeedback, relaxation, education and cognitive therapy on epilepsy in general (Level I).

Evidence of No Effect

Prophylactic phenytoin, carbamazepine and valproate have no effect on the prevention of late post-traumatic seizures.

PROGNOSIS

Patients with post-traumatic epilepsy are more likely to have poor behavioural and functional outcomes (Level III-2).

Common Health Issues in TBI

2 Somatic Complaints

FREQUENCY

Headaches (29-54%), dizziness (26-58%), pain (11-48%) and sleep disturbances (11-58%) are more common in people with TBI than the general population (Level III-2).

DIAGNOSIS

Self reported headaches, dizziness and sleep disturbances are the somatic complaints most likely to relate to TBI. However, somatic complaints are also common in people with chronic illness and disability. Self-reports of dizziness are particularly sensitive and specific to TBI patients. The Dizziness Handicap Inventory(*) (DHI) is a useful and reliable method for evaluating the efficacy of antivertigo/dizziness drugs (Level IV).

TREATMENT

Evidence of Effectiveness

Vestibular rehabilitation (including exercise therapy) is effective in the early stages of dizziness (Level II). Betahistine 48mg daily for eight weeks halved the dizziness handicap scores of TBI patients at six weeks compared with flunarizine (not available in Australia) (3.6 points compared with 7.5 points) (Level II).

Insufficient/Conflicting Evidence

There is no evidence for the effective management of headaches and sleep disturbance specific to TBI patients.

PROGNOSIS

The natural history of somatic complaints in TBI patients is not well documented, although two studies indicate that they are just as common five years after injury as they are at ten years post-injury (Level III-2).

Common Health Issues in TBI

3 Post-concussion Syndrome

FREQUENCY

Post-concussional syndrome (PCS) occurs in up to 15% of TBI patients but is probably no more common in TBI patients than others with chronic pain and trauma (Level I).

DIAGNOSIS

The Rivermead Post-concussional symptoms Questionnaire(*) (RPQ) is a useful tool for identifying patients with this syndrome (Level II).

TREATMENT

Evidence of Effectiveness

Brief cognitive and educational interventions shortly after injury are effective strategies for reducing PCS frequency and severity (Level II).

There is some evidence that individualized homeopathic remedies are more effective than placebo in reducing the frequency and severity of PCS in mild TBI patients (Level II).

Insufficient/Conflicting Evidence

There is insufficient evidence for the effectiveness of full bed rest for the prevention of PCS in TBI patients (Level II).

PROGNOSIS

The majority of PCS symptoms will resolve within 3 months of injury (Level I).

Mental Health Care in TBI

1 Depression

FREQUENCY

Major depression occurs in approximately 27% of TBI patients. There is a 1.5 times higher lifetime chance of depression in TBI compared with non head-injured patients (Level III-2).

DIAGNOSIS

'Feelings of hopelessness', 'difficulty enjoying activities' and 'feeling worthless' are the most distinguishing symptoms of depression in TBI patients. Difficulty falling asleep, restlessness weakness and poor concentration are also common but not as specific. Commonly used depression scales such as the Beck Inventory may not be as valid in TBI patients as in the general population (Level IV).

TREATMENT

Evidence of Effectiveness

Desipramine is an effective treatment for depression in TBI patients but may have harmful side effects (Level II). Sertraline may be effective yet less harmful alternative (Level III-2).

Community-based outreach rehabilitation twice weekly may be an effective treatment for depression in the first two years post-injury (Level II).

Evidence of No Effect

Aerobic exercise programs have no effect on depression in TBI patients (Level II).

PROGNOSIS

Depression will resolve in more than half of TBI patients (Level III-2).

Mental Health Care in TBI

2 Anxiety

FREQUENCY

Estimates of the prevalence of anxiety disorders in TBI patients are affected by variability in measurement and diagnosis. Prevalence may be of the order of 10-20% with post-traumatic stress disorder, obsessive-compulsive disorder and generalised anxiety disorder being much more likely to occur than phobias (Level III-2).

DIAGNOSIS

No TBI-specific measures for diagnosing anxiety disorders were found.

TREATMENT

Evidence of Effectiveness

Cognitive therapy appears to an effective intervention for the prevention of PTSD in TBI patients compared with repeat assessments and self-help booklets (Level II).

PROGNOSIS

It appears that anxiety disorders may be more common shortly after injury but reduce gradually over time (Level III-2).

An extended period of unconsciousness may be somewhat protective against the development of PTSD (Level III-2).

A history of psychiatric illness increases your risk of TBI (OR=1.6) (Level III-3).

Mental Health Care in TBI

3 Schizophrenia

FREQUENCY

Schizophrenia is around twice as common in TBI patients than in the general community (Level IV).

DIAGNOSIS

TBI patients with schizophrenia or a schizophrenic-like psychosis (SLP) are likely to present with paranoia and auditory hallucinations of gradual onset (Level III-3).

TREATMENT

Insufficient/Conflicting Evidence

In view of a lack of evidence about treatment of schizophrenia in TBI patients, the evidence for efficacy of newer antipsychotic agents in non-TBI patients should be considered. Risperidone and carbamazepine may be effective (Level I).

PROGNOSIS

The natural history of schizophrenia and SLP is likely to be subacute or chronic although data is very limited on this (Level III-2).

Cognitive and Behavioral Problems in TBI Patients

1 Cognitive Impairment

FREQUENCY

Self-reported memory problems, difficulty writing letters and dealing with paperwork are more common in TBI patients compared with lower limb-injured controls. The prevalence amongst TBI patients 5 years post-injury increases with injury severity. Two-thirds of severe TBI patients report memory problems, 44.4% have difficulty writing a letter and 59.3% have trouble dealing with paperwork (Level III-2).

DIAGNOSIS

The cognitive subscale of The Institute of Rehabilitation and Research (TIRR) checklist(*) has a high proportion of items that are potentially useful for screening TBI patients for cognitive dysfunction (Level III-2).

TREATMENT

Evidence of Effectiveness

Memory aids and reminder devices can reduce the number of everyday memory failures in TBI patients. Cognitive rehabilitation can also reduce anxiety and improve self-concept and interpersonal relationships in TBI patients. There is no evidence that cognitive rehabilitation improves health or employment outcomes (Level I).

Insufficient/Conflicting Evidence

There is inconclusive evidence for the effectiveness of dopamine agonists for improvement of memory and executive functions in TBI patients (Level II).

Evidence of No Effect

Mindfulness meditation techniques have no effect on cognition in TBI patients (Level II).

PROGNOSIS

Cognitive deficits usually resolve in mild TBI patients within one to three months of injury. Cognitive improvement may continue in moderate –severe TBI patients for up to 2 years (Level III-2).

Cognitive and Behavioral Problems in TBI Patients

2 Personality and Behaviour Changes

FREQUENCY

Behavioural problems may occur in more than half (61.6%) patients 12 months after injury. They may be more than twice as common in TBI patients as patients with lower limb trauma and are more likely to have a depressive temperament. Irritability, impatience and socialisation problems are the more common behavioural issues following TBI. They are more frequent in patients with severe TBI (Level III-2).

DIAGNOSIS

The Neurobehavioural Functioning Inventory(*) (NFI) (carer-rated), Neurobehavioural Rating Scale-Revised(*) (NRS-R) (clinician-administered) and The Institute of Rehabilitation and Research (TIIR) (self-report) are all potentially useful tools for assessing and monitoring behavioural outcomes of TBI. Bias in these measures however, is likely and it may be useful to use more than one in practice (Level III-2).

TREATMENT

Insufficient/Conflicting Evidence

There is no definitive evidence for the effectiveness of drug therapy for behavioural problems in TBI patients. There is weak evidence, mainly based on case studies, that psychostimulants are effective in the treatment of apathy, inattention and slowness; high dose beta-blockers for agitation and aggression; anticonvulsants and antidepressants (particularly SSRIs) in the treatment of agitation and aggression (especially in the presence of an affective disorder). Lithium and dopaminergic drugs may have adverse effects in some patients (Level I).

There is some evidence that anger management is an effective treatment for TBI patients with anger problems (Level II).

PROGNOSIS

Behavioural problems appear likely to be chronic. It is possible that 63.0% severe TBI patients suffer from irritability and 40.7% with depressive temper five years post-injury (Level III-2).

Lifestyle Issues and Quality of Life

1 Common Lifestyle Consequences and Quality of Life to TBI Patients

FREQUENCY

Lack of consensus about a definition for Quality of Life (QoL) in TBI patients has resulted in an absence of validated TBI-specific assessment tools. (Level I)

People with severe TBI are likely to perceive their quality of life as normal whereas those with mild TBI will rate QoL as worse. (Level III-2)

Work, socializing, close friends and significant others are important unmet needs for TBI patients. (Level IV).

DIAGNOSIS

SF-36(*) is an internally consistent and reliable tool for identifying problems in relation to quality of life in individuals TBI. The Community Integration Questionnaire(*) (CIQ) is another reliable and valid measure in TBI patients. (Level IV).

TREATMENT

Insufficient/Conflicting Evidence

We found no effective strategies to improve QoL.

PROGNOSIS

Employment, particularly part-time work is an important prognostic indicator for QoL after TBI (Level III-2).

Caregiver perceptions of patient fitness to drive strongly influence driving levels but do not accurately predict driver safety. Medical assessment is a more accurate method of determining road safety (Level III-2).

Lifestyle Issues and Quality of Life

2 Functional Status Daily Living and Return to Work after TBI

FREQUENCY

Functional difficulties are more common in patients with severe TBI than in mild-moderate groups or controls with lower limb injuries. Functional difficulties are less common than cognitive difficulties in most TBI patients (Level III-2).

DIAGNOSIS

Most tools for measuring functional status have been designed for use in the acute and post-acute hospital setting. The Neurobehavioural Functioning Inventory(*) (NFI) and Patient Competency Rating Scale(*) (PCRS) appear to be the most clinically useful in the community setting (Level III-2).

Concurrent administration of the PCRS to TBI patients and significant others in severely injured patients may be a useful tool for identifying self-awareness problems (Level III-2).

TREATMENT

Insufficient/Conflicting Evidence

There is limited evidence for the effectiveness of individual placement and/or apprenticeship models of supported employment for TBI patients (Level I).

There is limited and conflicting evidence about the effectiveness of coordinated care and case management models for TBI patients (Level I).

PROGNOSIS

Functional status is dynamic but generally improves over the first two years following TBI. Predictors of final functional status are uncertain (Level III-2).

Lifestyle Issues and Quality of Life

3 Issues for Carers, Friends, and Family of TBI

FREQUENCY

Estimates of primary caregiver stress and family dysfunction vary considerably. They may be as low as 10% or as high as 68% (Level IV).

DIAGNOSIS

Primary carers (particularly wives) are at greatest risk of poor psychological outcomes. Male relatives (most of whom are secondary or tertiary carers) are likely to express their distress as anger or fatigue rather than depression or anxiety. This should be considered in assessing caregiver and family stress (Level IV).

The Family Needs Questionnaire(*) (FNQ) and the Caregivers Appraisal Scales(*) (CAS) have both been validated in TBI caregivers and found to be reliable and clinically useful (Level IV).

TREATMENT

Insufficient/Conflicting Evidence

Behavior management programs and provision of written material had no significant effect on reducing caregiver burden. There was inconclusive evidence about the effect of level of social support on reducing caregiver distress (Level III-2).

There is insufficient evidence for the effectiveness of education and case management programs on caregiver stress and burden in families of TBI patients (Level I & II).

PROGNOSIS

Caregiver stress is greater if the TBI sufferer has a psychosocial history and in those who have financial barriers to accessing services. Social support structures may play an important role in the prognosis for caregiver burden (Level III-2).

Substance Abuse

FREQUENCY

Alcohol use is frequently related to TBI with high pre-injury alcohol use in most populations studied (Level III-2).

Younger TBI patients and those who had high pre-injury consumption levels are most at risk of post-injury alcohol abuse. There is conflicting evidence about the post-injury patterns of alcohol use although one study over a longer time period suggests that use increases with duration since injury (Level III-2).

42% head injured patients were legally intoxicated (above 100mg/dL) blood alcohol level on presentation in emergency department.

DIAGNOSIS

The CAGE questionnaire for alcohol abuse has 86% specificity and 91% sensitivity following TBI. The SASSI-3 was suggestive effective tool in screening for drug abuse in individuals with TBI.

TBI patient self-reports of alcohol use may be fairly reliable (Level IV).

Once problem drinking is identified it may be best to use more detailed multidimensional and composite measures (Level III-2).

TREATMENT

Insufficient/Conflicting Evidence

There is limited evidence that comprehensive case management in TBI patients with alcohol problems increases employment, community integration and physical well-being compared with no case management. There is also limited evidence that Systematic Motivational Counseling improves motivational structure and possibly reduces substance use (Level II and Level III-2).

PROGNOSIS

There is some evidence that alcohol use declines in the first year following TBI but may increase gradually over subsequent years (Level III-2).

Notes

A series of horizontal dotted lines for writing notes.



The University of Sydney