

Pragmatic Evidence Based Review

Community Integration in moderate to severe Traumatic Brain Injury

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Important Note:

- This report is not intended to replace clinical judgement, or be used as a clinical protocol.
- A review of evidence based guidelines, systematic reviews and high quality primary evidence relevant to the focus of this report was carried out incorporating the principles of systematic review. This does not however claim to be exhaustive.
- The document has been prepared by the staff of the research team, ACC. The content does
 not necessarily represent the official view of ACC or represent ACC policy.
- This report is based upon information supplied up to 12th May 2011

Purpose

The purpose of this report is to;

- Present the concept of Community Integration (CI)
- Report, where available, models of best practice for effective Community Integration following moderate to severe Traumatic Brain Injury (TBI)
- Describe those approaches/strategies reported in the literature as being effective for CI for those people who have sustained a moderate to severe TBI

This report is focused on moderate to severe TBI* in and adults.

The first section aims to clarify terms used throughout the literature and clarify those presented in this report.

Lay Summary

Community Integration (CI) is a multidimensional concept. The most important factors are; for the patient to be occupied, to have somewhere to live and to maintain & build

Based on the classifications of moderate to severe TBI used in; the ACC TBI Guideline (2006)1. NZGG. Traumatic Brain Injury: Diagnosis, Acute Management and Rehabilitation. Evidence based best practice guideline (ACC). In: ACC, editor. New Zealand: NZGG, 2006. From here on in the report, TBI will refer to this classification.

relationships with people. The Community Integration Questionnaire (CIQ) is a tool used to measure CI and has been shown to have good proxy subject agreement. The severity of a traumatic brain injury (TBI) is a strong predictor for how well a person with TBI will recover and reintegrate back into the community. The severity of TBI can be measured using the Glasgow Coma Scale (GCS) and the Post Traumatic Amnesia (PTA) scale. Following TBI people reintegrate back into the community to different degrees, younger people who were working prior to injury often don't integrate as well when compared to older people. There 9 different Community Integration rehabilitation programmes for TBI clients, including; Multidisciplinary programs (targeting physical, social, emotional and behavioural issues), Intensive residential programs (in supported housing), Neuro-behavioural programs, Communication training, Involvement in peer support groups, Intensive case management, Social community based programs and Post-acute rehabilitation programs. A multidisciplinary rehabilitation program appears to be the most effective approach to help people with traumatic brain injury reintegrate into the community

Key findings

- CI should be considered a multidimensional concept (Section 1, Page 3)
- Although definitions of CI vary across the literature, common themes emerge defining CI as; being occupied, having somewhere to live and maintaining & building relationships with people (Section 1, Page 3)
- Employment forms part of CI but has been considered in an independent report
- The literature does not define a gold standard tool for measurement of CI. The tool used must reflect outcomes of interest (Section 3.1, Page 4)
- The Community Integration Questionnaire (CIQ) is the most widely used tool to measure CI and has good proxy subject agreement (Section 3.1, Page 5)
- Severity of injury is a strong prognostic factor for CI and can be measured using the Glasgow Coma Scale (GCS) and the Post Traumatic Amnesia (PTA) (Section 3.2, Page 6)
- The literature defines 2 sub-groups within the moderate to severe TBI population; Low and High community integration groups (Section 3.2, Page 6)
- There are 9 variations of CI rehabilitation programs detailed in the literature for TBI clients. These programs include; multidisciplinary programs targeting physical, social, emotional and behavioural issues, Intensive residential programs in supported housing, neuro-behavioural programs, communication training; involvement in peer support groups, intensive case management; social community based programs; and post-acute rehabilitation programs (Section 3.3, Page 7)
- The strongest evidence is for a multidisciplinary rehabilitation program; however it is not apparent in the literature what is the optimal volume &/or intensity for the rehabilitation program (Section 3.3, Page 10)
- CI programmes improve outcomes and are more cost effective when the program commences within 90 days of injury (Section 3.3, Page 10)

Recommendations

- Use the CIQ and the Sydney Psychosocial Reintegration Scale (SPRS) to measure CI; dependent on outcomes of interest these may be used in combination or independently
- Use the GCS and PTA for predicting CI following TBI
- Employ the use of multidisciplinary CI rehabilitation programmes
- Refer clients into an appropriate multidisciplinary rehabilitation program within 90 days of injury

- Volume and intensity of rehabilitation program components should be dictated by needs of client
- It would be instrumental for ACC to collect data over a longer period of time post injury for each TBI client. This would allow closer monitoring of the client to ensure they maintain CI. It would also highlight the need for re-intervention.

1. Background

The concept of Community Integration

Community integration and community reintegration are used synonymously in the literature. For the purposes of this report Community Integration (CI) will be used.

Many researchers consider that CI should be the goal of all TBI rehabilitation programs²³. CI is a broad, multi-dimensional concept that includes, but is not limited to; helping individuals with gaining independence in living; obtaining a residence; maintaining a social support network; and engaging in productive activity; all of which are significantly impacted by TBI ⁴⁵. The multifaceted nature of CI presents difficulty in adequately defining it. In the absence of a clear definition of CI it is difficult to measure if a person has achieved CI.

Many definitions of CI exist within the literature; outlined in Table 1.

Table 1: Definitions of CI

Author	Definition of CI
Jacobs 1993 ⁶	Colloquially defined as;
	1) Something to do
	2) Somewhere to live
	3) Someone to love
Willer et al 1993 ⁷	3 related categories:
	(1) Integration into a homelike setting
	(2) Social integration
	(3) Integration into productive activities
McColl et al 1998 ³	Four-dimensional CI model consisting of:
	(1) General integration
	(2) Independent living
	(3) Occupation
	(4) Social support
Dijkers 1998 ⁸	Priorities and opportunities for people in the least restrictive environments
McColl et al 2001 ⁹	CI is the experience of being a part of the community, being accepted, and not being unduly disadvantaged because of the disability
	This definition was threefold:
	1) Activities to fill one's time,
	2) Independence in one's living situation
	3) Relationships with other people

Author	Definition of CI
McCabe 2007 ⁵ ; Reistetter 2005 ⁴	Broad, multi-dimensional concept Includes, but is not limited to;
	Helping individuals with gaining independence in living
	2) Obtaining a residence
	3) Maintaining a social support network
	4) Engaging in productive activity
Kim & Colantonio 2010 ¹⁰	Settling clients into communities where they can be happy and productive
	2) Providing opportunities for people in the least restricted environment.

There are three themes common to all of the above definitions. Cl involves:

- 1). Relationships with others
- 2). An independent living situation
- 3). The need to have activities to occupy one's time.

2. Methodology

A comprehensive literature search focused on moderate to severe TBI was undertaken by an information specialist. The following databases, websites and search tools were used to identify primary and secondary studies; AMED, Cochrane Library, Embase, Global Evidence Mapping Initiative (TBI section), Medline (and Pre-Medline), NHS CRD databases, NHS Evidence, TRIP database. Additionally the following sites were used to identify guidelines: Australian Clinical Practice Guidelines Portal, Guidelines International Network (GIN) database, National Guideline Clearinghouse, SIGN (Scottish Intercollegiate Guidelines Network). The keywords "Brain Injuries", "Community Integration", "Community Reintegration" were searched and also combined. The search was limited to the English language and humans 2004 – 2011. The literature was critically appraised using SIGN¹¹ grading for systematic reviews and Randomised Controlled Trials (RCTs), and the AGREE¹² instrument for appraisal of guideline quality.

3. Review of the Literature

People with a history of TBI have been less well integrated into their communities than the general population¹³. Post acute TBI rehabilitation has become vital in returning TBI patients to their homes and communities¹⁴.

TBI affects, to varying degrees, cognitive, behavioural and physical function which may impact on participation in life.

This section of the report aims to address CI in TBI clients. CI strategies to facilitate CI following TBI will be discussed.

3.1 Measuring CI

A number of tools for measuring CI are reported in the literature^{4 10}. There is no one tool that has been shown to be most efficacious, however the Community Integration Questionnaire⁷ (CIQ) appears to be the most widely used⁴.

The tools all differ slightly and have their strengths and weaknesses, Reistetter & Abreu⁴ recommend selecting the appropriate tool to measure the outcomes of interest. The tools and their concepts are detailed in Table 2.

The CIQ has been shown to have good proxy subject agreement⁴. Craig Handicap Assessment Reporting Technique (CHART) is reported as the second most widely used tool. Both the CIQ and CHART report at the handicap level; however the CHART provides additional information on occupation, cognition and social function. CHART takes longer to administer than CIQ.

Table 2: Measurement tools for CI

Tool	Concepts/measures/properties
CIQ (Community	Objective and shows good validity and reliability
Integration Questionnaire)	Well established for sensitivity within TBI
	Measures performance at the handicap level
	Based on WHO international classification of impairments, disabilities and handicaps
	Revised scoring procedures validated and strengthens tool
	Quick to administer
	Good proxy subject agreement; increases utility
	Best evidence in terms of validity, reliability and frequency of use throughout the literature
SPRS (Sydney	Subjective client centred measures
Psychosocial Reintegration Scale)	Obtains subjective information specifically in the areas; occupational activities, relationships and independent living skills
	Not extensively used but comparable to the CIQ subscales
CHART (Craig Handicap	Measures at the handicap level
Assessment Reporting Technique)	Provides additional info on occupation & cognitive and social functions increasing utility
	Longer time to administer than CIQ
CIM (Community Integration Measure)	Subjective, client centred measure
BICRO-39 (Brain Injury	Newer tool
Community Rehabilitation Outcome)	The only tool to be included in an RCT
	39 subscales to measure a variety of areas from activity performance to psychosocial issues and general

Tool	Concepts/measures/properties
	participation
	Captures additional information not present on CIQ or CHART
RNL (Reintegration to Normal Living scale)	Subjective client centred measure
Normal Living Scale)	Reflects client satisfaction with increased functional performance

The outcomes of interest should dictate the tool for measuring CI. If subjective information is critical to the decision process the CIM or SPRS could be used. If objective information is sought; CIQ or CHART could be recommended at this stage; given the quicker administration time of the CIQ this tool may be preferable. As more evidence around it's use becomes available, consideration could be given to the BICRO-39.

A combination of the CIQ and the SPRS are recommended to gather subjective and objective information to inform the rehabilitation needs of the client. The GCS and PTA are recommended for use in predicting CI following TBI.

3.2 Prognostic Factors for CI

Understanding prognostic factors for CI is essential to implementing a successful CI rehabilitation program. Winkler et al¹³ reports that when considering CI, two subgroups can be identified within the TBI population; high and low CI groups. Of eight personal factors examined only one was significantly different between the high and low CI groups; age at time of injury with the younger group showing lower CI. This finding is somewhat inconsistent with previous studies¹⁵⁻¹⁸. These studies found age at time of injury to be significant but reported that the population had a higher CI. Interestingly the methodological difference between that of Winkler et al and the previous studies was that Winkler included patient perception of their CI. This perhaps highlights the need to include; where possible; clients perceptions as a measure of CI.

Following a comprehensive systematic review⁴ regardless of study design, the following prognostic factors have been consistently identified;

- Severity of injury (as measured by GCS and PTA)
- Age
- Gender
- Education
- Prior work and living arrangements
- Cognitive and emotional status
- Functional performance
- Disability

The literature also highlights evidence^{13 19} to suggest that discharge destination is a prognostic factor for CI. Those with low CI tend to go to another hospital, group home or the home of a relative and may consequentially experience more activity restrictions. Those with higher CI tend to return to their pre-injury home¹³.

Consideration should be given to the above factors when considering appropriate CI rehabilitation programs; aiming to address the existence of those factors most likely to impede CI (mentioned above).

3.3 Facilitating CI

In mild TBI it has been reported that CI programs have no impact on outcomes¹⁰. This is not the case however for moderate to severe TBI. It is evident that CI programs show positive results, improve outcomes and should therefore be considered for people with TBI^{10 20}. Successful CI is underpinned by the quality, uptake and success of rehabilitation interventions addressing specific life skills (i.e. memory, communication, motor and social functioning) that assist individuals to regain participation in society^{4 5}.

There are a number of CI models/programs represented in the literature outlined in Tables 3 and 4

Table 3: Programs to facilitate CI¹⁰

Study	Design and participants	Intervention
Cicerone, Mott, Azulay, & Friel (2004), United States	Non-randomized controlled trial	Intensive cognitive rehabilitation
	Treatment group (n=27): Age=37.8 ± 10.6, 63% male Control group (n=29): Age=37.1 ± 12.0, 79% male Injury severity: Moderate/severe (89%)	Structured & integrated 16-wk program: Compensation for cognitive deficits, communication skills, psychotherapy, family support Occupational Therapist and Physiotherapist involvement
Constantinidou et al. (2005), United States	Nonrandomized controlled study, matched design Treatment group (n=14): Age=32.2 ± 11.4 gender not reported Injury severity: Moderate/severe	Intensive cognitive rehabilitation Systematic categorization training; 3–5 hr/wk, 10–12wk Improvement on Home Integration & Productive activity scores No changes in Social Integration

Study	Design and participants	Intervention
High, Roebuck-Spencer, Sander, Struchen, & Sherer (2006), United States	Prospective cohort, Pre & post test Group 1 (n=115): >6 months Post-injury, age=31.5 ± 11.5, 70.7% male Group 2 (n 5 23): 6–12 months, age=32.8 ± 10.6, 60.9% male Group 3 (n=29): >12 months, age=27.2 ± 8.9, 62.1% male Injury severity: Moderate/severe	Comprehensive-integrated program Intervention group: Environmental supports, counselling, simulated activities in the community for 4 months Occupational Therapist, Speech & Language therapist, psychologist and vocational specialist involvement
Powell, Heslin, & Greenwood (2002), United Kingdom	Randomized controlled trial Treatment group (n=48): Age=34 ± 11, 77.1% male Control group (n=46): Age=35 ± 10, 73.9% male Injury severity: Severe	Multidisciplinary rehabilitation Intervention group: OT, PT, SLP, and counselling from psychologist and social worker, 2–6 hr/day, 6–12 wk Intervention group had significantly better BICRO–39 total scores and two BICRO–39 subscales, self organization, and psychological wellbeing
Goranson, Graves, Allison & La Freniere (2003) Canada	Non-randomised case- control, pre & post test Treatment group (n=21), Age 34.7±12.4, 43% male Control group (n=21), Age 36.6±12.5, 38% male Injury Severity: mild/moderate	Multidisciplinary rehabilitation Intervention group: intensive outpatient rehabilitation program, Occupational Therapist, Physiotherapist, Speech & Language Therapist, recreation therapy, social work, psychology. 4 days/week, 5.5_hrs/day, 4 months Intervention group higher total CIQ scores; Home integration, Social integration and productivity

Table 4: Evidence available for CI program interventions

Approach	Evidence
Multidisciplinary Rehabilitation in the Community (Interventions are delivered locally, based on	3 RCTs
	1 pseudo RCT
individual needs and entitlements)	1 non-randomised experimental trial (NRET)
	1 case series
	(4 USA, 1 Australia, 1 Canada, 1 Sweden, 1 UK. 6 Adult population, 1 paediatric, 1 mixed)
Residential Brain Injury – Specific	1 NRET
Community Reintegration Training (Intensive rehabilitation in	6 case series
supported housing shared by adults with TBI)	1 case report
	(4 USA, 2 Canada, 1 Hong Kong, 1 The Netherlands. & adult populations, 1 mixed)
Neuro-behavioural programs	1 RCT
	1 Case series
	1 Case report
	(2 USA, 1 Australia)
Communication Training	1 retrospective cohort study
	(USA, adult population)
Comprehensive Group Day	2 RCTs
Treatment program (Full-time, regular meetings with peers to facilitate teaching and testing of group, social & communication therapies)	3 NRETs
	1 Prospective cohort study
	3 Case series
	(5 USA, 1 Canada, 1 Finland, 1 Japan & 1 The Netherlands. Adult population)

Approach	Evidence
Support Group plus Individual Therapies (Deliberate, directed formation of TBI peer support groups, often with individual counselling)	3 Case series 2 Case reports (5 USA. 4 adult, 1 Paediatric)
Intensive Case Management, leading to Referrals in the Community	1 NRET (USA adult population)
Directed Leisure and Social Programs in the Community	Prospective cohort study Case series (1 Australia, 1 USA. Adult populations)
Various Post-Acute Rehabilitation Programs Addressing Community Reintegration	1 Systematic Review of RCTs & NRETs

Comparison across existing studies of CI intervention programs is problematic as studies are conducted in a variety of settings and include participants across a wide range of TBI severity with differing clinical characteristics. However Tables 3 and 4 collectively show that stronger evidence appears to be emerging for multidisciplinary rehabilitation and cognitive rehabilitation programs.

Multidisciplinary rehabilitation has been shown to be more effective for achieving CI when compared to a less structured and intensive programme²¹, a home based programme²² or no intervention²⁰. Further to this there is evidence that early referral of TBI clients into such programs (within 90 days of injury) improves outcomes and is more cost effective^{23 24}.

Multidisciplinary programmes typically involve a team approach that includes; Recreation Therapy, Occupational Therapy, Physical Therapy, Speech Therapy, Social Work, Neuropsychology and Physiatry²⁰⁻²². The goal of the programme is to assist individuals with TBI to learn ways to overcome the effects of their injury and to maximize their functional capacity. This is done through teaching compensatory strategies for cognitive, physical or emotional difficulties occurring as a result of injury. The team identifies and agrees therapeutic goals with the TBI client. A comprehensive care plan is then formulated; comprising appropriate treatment and education for the client.

The literature does not yet define quantities for optimal treatment volume and intensity within the rehabilitation program. This does not appear to have been specifically studied. Reported volumes and intensities vary from 2-4 days/week, 2-6 hours/day, for 3-6 months. In the absence of such evidence it is recommended that the clients' needs dictate the 'quantity' of treatment included in the CI rehabilitation program.

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