Social Reintegration of Traumatic Brain-Injured: 
the French Experience

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Traumatic Brain Injury (TBI) may lead to specific handicap, often hidden, mainly due to cognitive and behavioural sequelae. Social re-entry is a long-term, fluctuant and precarious process. The French experience will be illustrated by 6 initiatives answering to 6 challenges to do with TBI specificities:

1. bridging the gap, between initial rehabilitation and community re-entry, via transitional units dealing with assessment, retraining, social/vocational orientation and follow-up. Today, there are 30 such units based on multidisciplinary teams.
2. assessing recovery by TBI-specific and validated evaluation tools: EBIS holistic document, BNI Screening of higher cerebral functions, Glasgow outcome extended, and QOLIBRI, a TBI-specific quality of life tool.
3. promoting specific re-entry programmes founded on limited medication, ecological neuro-psychological rehabilitation, exchange groups and workshops, violence prevention, continuity of care, environmental structuration, and “resocialisation”.
4. taking into account the “head injured family”
5. facilitating recovery after sports-related concussion
6. facing medico-legal consequences and compensation: In that perspective, we developed guidelines for TBI-specific expert appraisal, including mandatory neuro-psychological assessment, family interview and an annual forum gathering lawyers and health professionals.

Keywords: traumatic brain injury, community reintegration, assessment tools, long-term, rehabilitation programmes

INTRODUCTION

In developed countries initial care and rehabilitation services are well-equipped for traumatic brain injured people (TBI), especially for the severely injured (1).

One of the main challenges - and perhaps the most difficult to achieve - concerns the so-called third phase after initial rehabilitation: reintegration into the community. All countries struggle with this third phase and the question is how to cross the bridge between medical care/rehabilitation and social reintegration? (2, 3). This paper discusses the situation in France as it has evolved over the past 20 years.

Bridging the gap between rehabilitation and social reintegration

As a person recovers from their TBI, bridging this gap means changing semiology from a medical-oriented health care perspective to a more psychological and social one. There are three reasons this transformation is so difficult.

The first is related to the organization of trauma health care services. In the initial instance the priority is to save lives through providing rapid and sophisticated emergency tertiary care. The demand for these services, which are visible services at the high end of technological and rehabilitation medicine, sets the perspective on TBI recovery. In contrast,
long-term medical support and lower-level rehabilitation do not the same profile or priority in either decision-makers’ minds when allocating resources or in the popular press and imagination. The consequence is that whilst immediate life-saving care may be highly developed and efficient, there may be a gap in care coordination following discharge from hospital or residential rehabilitation.

The second is based on the difficulty of leaving the hospital cocoon for the “real world”, particularly for those with ongoing mild or moderate cognitive and physical problems. For those with severe problems, they may never leave residential support care. For those with mild sequelae, the adjustment back into their former lives in the community may be slow and painful. For a sizable proportion of these cases, their intimate, family and friendship groups may irretrievably fracture, they may confront changes in their personality, and reduced economic opportunities due to ongoing disability. This second challenge reflects the necessity of taking into account the specificities of TBI’s handicap, especially in the long term.

The third reason relates to the mental health of the patient. Physical recovery or improvement usually takes place during the first year after injury (1). This is the first aim of initial care and rehabilitation, as described above. However, the more distant the accident is, the more prominent the mental health component of a person’s handicap becomes. There are two key components affecting mental health: cognitive disorders and mood disturbances. Both are more important than physical function.

Generally, following a TBI cognitive recovery will take about 2 years, after which few (if any) further gains are reported. Cognitive disorders may lead to restrictions in both executive and motor functions, directly causing difficulties with the adjustment issues described above. In particular reduced cognitive function may lead to giving up pre-injury work levels and being forced to accept work with lower levels of responsibility or to being unemployed. Both have direct consequences for a person’s economic resources.

Mood and behavioural disturbances consequent upon the experience of the trauma itself, ongoing physical disabilities and increasing awareness of cognitive losses are, above all, the main factor in continuing TBI handicap. These disorders fluctuate precariously year after year, for the rest of a person’s life. The most commonly reported long-term outcome, other than obvious physical disabilities, is depression. Depression has been reported in the literature as affecting ~25% of those with TBI and it has implications for various behavioural disorders, including the breakdown of intimate relationships, increased social isolation, poor work function and poor quality of life. Behavioural disorders have a multi-factorial aetiology: lesional, psychological and environmental (4).

These three reasons (the structural organization of medical and rehabilitation services, cognitive changes, and mood/behavioural disturbances) all pose significant challenges for social reintegration, but it is the psycho-social adjustment which is more important than the initial injury and on-going physical components. For example, initial TBI severity assessed by Glasgow Coma Scale is not correlated with quality of life for the years after injury (7). Regarding the importance of mood, however, it is instructive to consider Ben-Yishay’s recovery process (5), where 3 successive concepts represent as many key steps: awareness, acceptance and ego-identity.

These 3 steps assisting recovery involve paying significant attention to (6):

1) Motivation: a desire and personal engagement with rehabilitation;
2) Awareness and acceptance of the handicap and of subsequent limitations;
3) Emotion: sufficient emotional stabilization;
4) Environment: a family partner and an identified professional; and
5) Ego-identity: rebuilding one’s identity, a new ego.

What are, currently, the main challenges of TBI’s social reintegration in France?

The following list was derived from a 2-factor basis: current requirements from TBI and family associations as well as professional associations (8): The key issues were:

1. crossing the bridge between initial rehabilitation and social re-entry;
2. developing diagnosis tools, specific to TBI
including validation;
3. promoting TBI-specific re-entry programs;
4. taking into account the “head-injured family”;
5. paying attention to the numerous so-called mild-traumatic brain injured, in order to prevent the “miserable minority” that lives with long-term sequelae; and
6. improving medico-legal expertise and compensation.

HOW TO CROSS THE BRIDGE BETWEEN REHABILITATION AND RE-ENTRY?

Twenty years ago, there was hardly anything in France to bridge this gap. Indeed, the transition between hospital wards and citizenship looked like an exit towards an abyss. When it was time to go home, both the patient and family were full of hope, a hope for complete recovery and return to the time previous to injury; “the golden age”. Unfortunately, it was also the time for a growing awareness of lingering handicap, an excessive caregiving burden to be endorsed by the family and, last but not least, ongoing social isolation and reduced work or unemployment. The patient and family were confronted with a long-term chronic disability, hampered in many cases by epilepsy, fatigue, memory and mood disorders.

In 1995, we presented a new project to Mrs Simone Veil, the French Minister of Health, in order to promote specific answers to TBI needs, including a transitional program between rehabilitation and community re-entry. This project was selected and implemented by an official act of Government one year later. Initially, 10 units opened in Spring 1997; today, there are 30 units across France. There are four aims: evaluation, retraining, social and vocational orientation, and follow-up (UEROS) (2). Each unit, usually located within a rehabilitation centre or in an orientation centre, is composed of a multidisciplinary team, including full or part-time psychologists, speech-therapists, occupational therapists, job coaches, social workers and secretaries. UEROS provide support for a maximum of 6 months, which, where needed, may be repeated once. The UEROS are dedicated mainly to TBI-injured people (67%), and to other acquired brain injuries (ABI): stroke in young people (15%) and other encephalopathies (alcohol, AIDS, various infections and anoxia (18%). UEROS patients are assessed on a regular basis, including follow-up at 2 years post-discharge in order to evaluate the stability of their re-entry into the community.

Examination in 2008 of 395 UEROS ABI-patients led to the following Glasgow Outcome Scale score distribution, 2 years after discharge: 32% good recovery, 57% moderate, and 11% severe. It was also shown that 33% returned to their own accommodation and 49% to some kind of work.

A second initiative, in 2005 involved legal changes relating to the status of disabled people. Within this framework, one of the main innovations was the creation of a unique office in each of the 100 districts in France, the so-called “disabled people house”. Its main aim is to provide orientation and financial compensation to each disabled person.

A third decision, effective on April 1st 2010, is the creation of 26 regional health agencies which gather both medical and medico-social fields.

ELABORATING AND PROMOTING TBI-SPECIFIC ASSESSMENT TOOLS

The French situation is characterised by a paradoxical situation: on the one hand, centralised administration and social security and, on the other hand, a strong individuality of regions and people. While that centralisation has favoured setting up the UEROS centres across France, it is more difficult to encourage them to adopt validated, TBI-specific and universally distributed outcome measures in preference to local idiosyncratic measures which may not have the necessary developmental work behind them. To encourage the adoption of standard outcome measures, these have been advocated by regional forums of the national professional association “France Traumatisme Crânien”, through international congresses, and via international teams especially promoted to elaborate and validate TBI-specific assessment tools. As a result of these initiatives, four TBI-specific tools have emerged over the last decade; each covers different areas of life. All four have been translated into French and validated.
The first one, funded through a grant from a European commission project, is the E.B.I.S. document, promoted by the European Brain Injury Society (9). It is a holistic measure comprising 175 questions covering screening, medical, psychological and social aspects of life. Although the EBIS document is comprehensive, it takes about 2 hours to be completed. This is the main reason it has been used by few research teams. Its main application is in clinical research and there are few publications. In contrast with the EBIS document, the other 3 tools require each less than 20 minutes to administer and are, consequently, used more frequently.

The second is the B.N.I.S. (Barrow Neurological Institute Screening of Higher Cerebral Functions) (11) measure, which was precisely validated for acquired brain-injury (12). The Mini-Mental State Examination (MMSE, 10) is the most universal and generic tool for providing neuropsychological assessment. The BNIS was developed because the MMSE is not sufficiently sensitive and specific enough to evaluate ABI. Developed in 2000, the BNIS has been translated and validated in French. It takes about 12 to 20 minutes to complete using a pocket leaflet. Generally speaking, a detailed neuropsychological assessment should be performed at least once, after discharge from rehabilitation. In addition, for out-patients and at followup, the rapid screening of higher cerebral functions may be particularly useful using the BNIS.

The third measure is the Glasgow Outcome Scale Extended (GOSE) (13). This is a TBI-specific functional disability scale which assesses, relative to pre-injury status, activities of daily living, familial, social, and vocational handicap. Although an early instrument which was developed in the mid-1970s, the GOSE is probably the most widely used outcome measure in TBI, worldwide. Part of its appeal is that it takes less than 10 minutes to complete.

The fourth measure, the QOLIBRI (Quality of Life After Brain Injury), assesses the life satisfaction or the health-related quality of life (HRQoL) of the participant (14). At present, it is the only TBI-specific HRQoL tool, and has been validated in six languages. Explicitly designed to capture the patient perspective, the QOLIBRI comprises 37 items to be filled out by self-report in ~11 minutes by those with mild and moderate ABI. However, for those with severe injuries, who have limited insight and communication, the help of an interviewer may be needed. Such proxy completion takes ~20 minutes.

It adds, to objective outcome measures, the subjective opinion of the patient. It This TBI quality of life tool has an added value as compared to the most universally used generic reference, the SF-36, especially to evaluate cognition and feelings. 59% of the variance of the QOLIBRI is explained, in descending order, by depression, amount of help needed, comorbidity, anxiety, Glasgow Outcome Scale Extended, e.g. : emotional status, autonomy, health-status, disability.

A fifth measure which has been widely used in ABI, although not a TBI- or ABI-specific one, is the Community Integration Questionnaire (15).

PROMOTING TBI-SPECIFIC RE-ENTRY PROGRAMMES

To support people while they make the transition from hospital/rehabilitation into the community, we have in France day-care welcome centres, mobile teams for at-home help, sheltered work-centres, and residential facilities. Although we have these teams, unfortunately there are insufficient to meet the demand.

These programmes are mainly public and are funded by social security and local county administrations. The necessity of this is shown by the high cost of participation, particularly for residential programmes which can cost up to 220 euro a day. The various programs are grouped in the same area in Bordeaux, Angers and Mulhouse for example. This grouping enables the patient to successively benefit from these programmes. These programs offer a range of health services, viz.:

- The provision of required medications (16), taking into account the increased side effects in injured brain; side effects that are especially prevalent among psychotropic medications.
- The second aim is to offer an ecologically-based neuropsychological rehabilitation
program (17), explicitly oriented towards retraining skills, and teaching solving real life problems.

- Regarding psychological disorders, problem-focused coping strategies are used (18), including the use of communication peer groups for patients and families as well, and violence and maltreatment prevention programs (19).

In addition, there are local innovative holistic initiatives. Several examples are given that show the breadth of these.

- TBI-specific regional networks have been established. These provide networking opportunities for professionals and programmes for TBI-patients. Generally, these have been organised and funded by the public authorities. They exist mainly in Brittany, in the north of France and in the “Côte d’Azur”.

- Since 2005, ADEF-résidences have opened several ABI-specific residential facilities, including temporary courses and day-centres.

- Integrated programmes for TBI-patients, their families and the treating health care professionals (20). For example, in Bordeaux JM. Destaillats and JM. Mazaux developed a systemic program of this type.

- Academic initiatives in the areas of medicine and social rehabilitation. For example, in 2008, B. Pollez initiated, at the Catholic University of Lille, an academic program involving the medico-social field.

- Psychological restructuring programmes are also available. M. Onillon and JL. Truelle initiated such a program, based on the holistic programme of Ben- Yishay (5), in order to resocialise them, involving activities that took participants beyond rehabilitation centres and out into the community.

- There are a few specialist TBI-programmes for return to driving, which is widely regarded as an essential adult skill for independent living. The principal one is included in the rehabilitation centre at Mulhouse.

For those who do not need in-patient programmes, there are programmes involving “case-management” adapted to the French health care system. These programmes comprise a participating physician (a rehabilitation specialist or a neurologist) who sees the patient every 3 months; a health professional who follows the patient each week or every other week; a speech therapist (reimbursed by the social security); a psychologist; an occupational therapist or a social worker. The health professional takes the role of the case-manager and can dedicate some administrative, financial, or vocational tasks to other workers who he/she coordinates.

However, in spite of all these initiatives, there is limited evidence of the actual efficacy of these programmes (21, 22), including that there are few randomized trials. Although there are several reasons for this, four reasons may be particularly important. Re-entry programmes are more holistic than focused, making it difficult to assign causation of improvements to the programme. In these settings it is also difficult to conduct RCTs (randomised controlled trials) because comparisons with the control group is not easy and is particularly questionable (23). A third problem concerns studies where the participants act as their controls in pre-post settings. Many TBI-patients undergo spontaneous recovery and are in a plateau period before and after the programme. Finally, as mentioned above there are few TBI-specific outcome measures.

In an attempt to overcome some of these difficulties, to evaluate TBI-specific programmes, we intend to use the Commission for Accreditation of Rehabilitation Facilities (C.A.R.F.) (24). This is a non-profit American/Canadian organisation with 10-years of experience in the field during which it has assessed more than 500 programmes in North-America and in Europe, but not yet in France.

THE FAMILIES OF THOSE WITH HEAD-INJURIES

The family of those with a TBI suffers as well as the patient and caregiver (25). Indeed, the family is often the main caregiver (either a designated member or collectively) in the social reintegration period and in the long term where there are permanent disabilities or mood changes. From this perspective, families have to be trained on TBI specificities and care.

In France, some 50 local family associations are grouped in a national union (U.N.A.F.T.C.-
Union Nationale des Associations de Familles de Traumatisés Crâniens) which is linked with the association of health professionals working in trauma, the “France Traumatisme Crânien”. This relationship allows the transfer of expert knowledge and support to caregiving families.

Regarding support for TBI-children, the only comprehensive network covering from intensive care to social reintegration is in Paris. Paris also has a TBI-resource centre for specific information and training (including 5 university courses), documents on mild traumatic brain injury, “shaken baby”, parenthood and behavioural disorders.

RECOVERY IN SPORT-RELATED CONCUSSION (26, 27)

Although traumatic sporting injuries are quite common, little work has been in this field. In a programme developed by France-Galop, an organisation for horse races, we examined the concussions sustained by the 845 jockeys in France. In steeple-chasing, for example, we found that each jockey sustains one fall out of every 14 races! In 2008 those falls led to 94 cerebral concussions. In response to this situation we developed a short examination on the racetrack based on the most pertinent questions of the B.N.I.S. This was followed by a computerised assessment of the information processing speed (tachypsychia) via reaction time measurement after simple and progressively more complex tasks. If the diagnosis of concussion is made, the licence of the jockey is withdrawn for 5 days.

MEDICAL-LEGAL ASPECTS

If the head injury results from a traffic accident, insurance compensation enables the patient and his/her family to fund long term care. Following a commission required by the Ministry of Justice, we wrote guidelines for TBI-specific expert appraisal which could be used in court. For instance, 2 recommendations were mandatory: a neuropsychological examination and a family interview.

Moreover, since 1999 an annual forum is organised by E. Vieux to gather lawyers, TBI professionals, families and insurance companies in order to improve TBI expert appraisal and compensation.

Do these services meet the needs?

Little is known about the extent to which all the initiatives described above meet the needs of those who have suffered a TBI or the needs of their families. H. Lefebvre (8) interviewed TBI persons, families and professionals in Paris, Lyon and Bordeaux and reported that areas where services were inadequate included:

- Information, communication planning, a lack of understanding how different resources could be coordinated to provide coherent support, difficulties in obtaining feedback in progress and issues with record-keeping and access to health care plans or medical records.
- Financial protection, work adaptation and how to access care in psychological crises.
- Recognition of the family role, the need for family and caregiver training and support and the need for peer groups and associations.
- A lack of information about care continuity and how to achieve this and a lack of awareness of and access to TBI-specific programmes.

In short, despite the initiatives which have been put in place in France over the past 15 years, at the state, local and community levels, only a minority of all TBI and ABI patients are able to benefit from the re-entry system.

CONCLUSION

In-patients are primarily concerned with early neuro-rehabilitation, medication and other acute health care technologies. Generally, these involve focused acute care treatments, objective outcome measures and may draw on evidence-based medicine.

In contrast with the acute trauma health care sector, out-patients are concerned, later on, with social reintegration which implies a new semiology, not just limited to medical care, but also involving social and psychological care that is tailored to the needs of each individual living within his/her environment. In these circumstances, holistic programmes are needed and outcomes may be most appropriately assessed by HRQoL measures.

We have tried to describe in this paper, how
these longer-term needs are being met in France. Although there are many initiatives, it is also clear that these are insufficient to meet the needs of all those who have suffered a TBI.

Finally, “do not forget that a human life is not, whatever one’s feelings, a straight line between two perpendiculars but three lines either converging or diverging or crossing one another: what an individual wanted to be, what he thought he was, and what he actually was” (28).

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