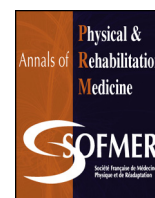




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## Review

# Behavioral and affective disorders after brain injury: French guidelines for prevention and community supports



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## ABSTRACT

**Objective:** The purpose of this study was to elaborate practice guidelines for the prevention of behavioral and affective disorders in adult outpatients after traumatic brain injury (TBI); but also to identify the support systems available for family, caregivers of patients with TBI within the community.

**Methods:** The elaboration of these guidelines followed the procedure validated by the French health authority for good practice recommendations, close to the Prisma statement. This involved a systematic and critical review of the literature looking for studies that investigated the impact of programs in community settings directed to behavioral and affective disorders post-TBI. Recommendations were then elaborated by a group of professionals and family representatives.

**Results:** Only six articles were found comprising 4 studies with a control group. Two studies showed a beneficial effect of personalized behavior management program delivered within natural community settings for persons with brain injury and their caregivers. Two other studies showed the relevance of scheduled telephone interventions to improve depressive symptoms and one study emphasized the usefulness of physical training. One study investigated the relevance of an outreach program; this study showed an improvement of the patients' independence but did not yield any conclusions regarding anxiety and depression.

**Discussion and recommendations:** In addition to the application of care pathways already established by the SOFMER, prevention of behavioral and affective disorders for brain-injured outpatients should involve pain management, as well as development of therapeutic partnerships. It is recommended to inform patients, their family and caregivers regarding the local organization and facilities involved in the management of traumatic brain injury. The relevance of therapeutic education for implementing coping strategies, educating caregivers on behavioral disorder management, follow-up telephone interventions, and holistic therapy seems established. The level of evidence is low and preliminary studies should be confirmed with larger controlled trials.

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## 1. Introduction

Traumatic brain injury lasts a few seconds while its consequences can linger for a lifetime. This radical rupture will considerably change the trajectory and the life project of patients with TBI and their closed ones. Several personal and environmental factors will influence the patient's mood and behaviors and eventually lead to excesses or contrarily to withdrawing from others. Epidemiological studies showed that behavioral disorders are one of the most frequent complications at a distance from a

severe traumatic brain injury [1,2]. It has been established that aggressive behaviors were correlated to the existence of a dysexecutive syndrome [3], anxiety or depression [4], pain [5], noisy environment [6], family dysfunction [7] or poor social functioning [8]. Furthermore, the risk of developing depression remains quite high at a distance from TBI, affecting about 30% of patients [9]. Several environmental factors promoting the onset of depression were also identified: isolation, low socioeconomic status, substance abuse, feuds... [10].

Furthermore, the severity of behavioral disorders like the patient's psychological state can explain for a big part the depressive state and burden felt by closed ones and caregivers [11,12].

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It is essential to take into account these different factors having mutual and reciprocal influences if one wants to attenuate behavioral disorders, depressive reactions as well as their family and society consequences when returning home, especially since a certain number of factors can be changed with adapted support.

To date, most studies concerned hospital care management, which is the first step of the care pathway for TBI patients (see the care pathway established by the French Society of Physical and Rehabilitation Medicine [SOFMER] [13]). This first hospital-based step is often quite short compared to the duration of behavioral and affective disorders triggered by the traumatic brain injury. In a retrospective study concerning 343 patients with moderate or severe TBI, 94% went home in the first year following the trauma [14].

Patients and their families are often powerless to cope with behavioral disorders once at home and their main expectations are long-term follow-up and interventions (see [15]). A few studies reported the effects of a post-hospitalization rehabilitation program in patients with TBI (e.g.: [16,17]) but most often, these studies did not specifically focus on the impact of behavioral or affective disorders.

The objective of our study was to determine follow-up measures beyond the hospital stay that could reduce behavioral disorders, depression and constraints for closed ones, based on data from the literature and experts' consensus.

## 2. Methods

In order to address the issue of follow-up and prevention of behavioral and affective disorders secondary to TBI, a review of the literature was conducted on the Medline database, in French and English between January 1990 and March 2012 (research conducted by the services of the French High Authority for Health according to the clinical practice recommendations). The research strategy on Medline was based on the combination of the following keywords:

("Craniocerebral trauma" [Majr] or "Brain injuries" [Majr] or (Brain injur\* or Brain trauma\* or Head injur\* or Head trauma\*) [title] and "General practitioners" [Mesh] or "Social support" [Mesh] or "Family practice" [Mesh] or "General practice" [Mesh] or "Continuity of patient care" [Mesh] or "Rehabilitation/organization and administration" [Mesh] or "Case management" [Mesh] or "Social work" [Mesh] or "Social work" [Mesh] or "Family therapy" [Mesh] or "Ambulatory care facilities" [Mesh] or "Family" [Mesh] or "Patient education as topic" [Mesh] or "Caregivers" [Mesh] or "Social support" [Mesh] or "Case management" [Mesh] or "Rehabilitation, vocational" [Mesh] or Community integration or social reintegration or return to work or community integration [title] NOT "Critical care" [Mesh] or "Child" [Mesh] or "Infant" [Mesh] or "Pediatrics" [Mesh] or "Adolescent" [Mesh] or (Critical care or child\* or infan\* or paediatr\* or pediater\* or adolescent\*). An additional study was performed up to 2015 without the use of the services of the French High Authority for Health. Finally, an additional research was conducted on books and articles not referenced in this database.

Only articles describing a support program upon discharge from the hospital or interventions aiming to treat, alleviate or prevent behavioral or affective disorders in patients with TBI after their hospitalization, were considered for this work. Studies with a control group, open studies without a control group, case series and clinical case reports were included in this review of the literature. Results from the articles retained were analyzed according to evidence-based medicine criteria (see Table 1 for the level of evidence and recommendation grades).

Recommendations were formulated by an expert group made of professionals (9 PM&R physicians, 4 psychiatrists, 3 psychologists,

**Table 1**  
Levels of evidence and grades of recommendations.

Level of evidence	Types of interventional studies	Grades of recommendation
1	High power randomized controlled trials (RCT) Meta-analysis of RCT	Grade A Established scientific evidence
2	Low-power RCT Non-randomized comparative studies Cohort studies	Grade B Scientific presumption
3	Case-control studies	Grade C
4	Comparative studies with considerable bias Retrospective studies Case series	Low level of evidence

1 primary care physician, 1 physical education professor, 1 social worker, 1 lawyer, 1 director of a medicosocial structure) and 2 persons representing the families of patients with TBI. Afterwards, these recommendations were read and criticized by a reading group also made of professionals (10 PM&R physicians, 7 psychologists, 2 head nurses, 1 psychiatrist, 1 neurologist, 1 primary care physician, 1 physician working in a prison setting, 1 physical education professor, 1 social worker, 1 physical therapist, 1 occupational therapist, 1 lawyer, 1 magistrate, 1 director of a medicosocial structure, 1 person representing the insurance companies and 2 representatives of associations of families of patients with TBI) (see introductory article of Mathé and Luauté in this issue). This good practice recommendation received the label from the French High Authority for Health, meaning that these recommendations were established according to the methodological guidelines and procedures recommended by HAS (see: [http://www.has-sante.fr/portail/jcms/c\\_431294/recommandations-pour-la-pratique-clinique-rpc](http://www.has-sante.fr/portail/jcms/c_431294/recommandations-pour-la-pratique-clinique-rpc); the website of the French High Authority for Health (HAS) gives access to documents in English). The protocol lists several criteria (criteria 1, 2, 3, 5, 6, 7, 9, 13, 15) of the PRISMA method [7].

## 3. Results

Overall, 980 articles were identified from the selected keywords; 146 abstracts were read and only 6 articles (329 persons included in the different protocols) answered the question asked and the criteria defined for this literature review (see Table 2 and Fig. 1).

More specifically for behavioral disorders, only 2 studies were found [18,19]. In the first one (level 2), on 47 patients with brain damage, including 24 with TBI, the frequency of behavioral disorders was evaluated in three different groups: a control group without changes to the usual care management, a therapeutic education program for caregivers (one 2-hour session weekly over a 4-week period) and a more comprehensive program that included a first phase of therapeutic education for 4 weeks, followed by a second phase of 8 additional weeks (according to the same frequency of one weekly session) dedicated to individualized help for behavioral disorders [18]. A significant decrease in behavioral disorders frequency was reported at the 3-month follow-up visit in the group that benefited from the comprehensive program vs the group that received only therapeutic education and the control group.

In a pilot study, a therapeutic education program for caregivers was implemented using a web-based, videoconferencing training to help manage behavioral disorders in patients with TBI. This study showed the feasibility of this type of program and the satisfaction of participants who, at follow-up, reported being able

**Table 2**  
Affective and behavioral disorders after traumatic brain injury: community-based rehabilitation programs.

References	Study description	Level of evidence	Main results and conclusion
Carnevale et al., 2006 [18]	RCT 47 brain damaged patients (24 TBI) at home and their caregivers 3 groups: (i) control ( $n = 17$ ); (ii) therapeutic education for caregivers ( $n = 14$ ) during 4 weeks (1 session per week) and (iii) therapeutic education for caregivers (4 weeks) + <b>individualized behavioral modification program</b> (8 weeks, 1 session per week) ( $n = 16$ ) Main outcome measure: change in frequency of targeted behavioral disorders immediately after, and 3 months after the program	2	No significant changes were noted in the frequency of targeted behavioral disorders immediately after the program. Significant decrease of the frequency of disruptive behavioral disorders at 3 months post-termination compared to education only and to the control group
Sander et al., 2009 [19]	Feasibility study 15 caregivers of persons with TBI Six <b>web-based videoconferencing</b> sessions for caregivers to manage cognitive and behavioral problems, combining didactic education and interactive problem-solving Outcome: satisfaction and perceived utility questionnaires immediately following training and, on average, 18 months after training	4	Participants' overall satisfaction and comfort with the training. They perceived that they gained knowledge that was applicable to the everyday problems. At follow-up, all participants reported having used the knowledge gained to help cope with problems. The questionnaire highlighted obstacles related to willingness to seek help among persons in rural areas
Bombardier et al., 2009 [20]	Single-blinded, RCT comparing a <b>scheduled telephone intervention</b> to the usual care 171 TBI patients discharged from an inpatient rehabilitation unit The treatment group received up to 7 scheduled telephone sessions over 9 months designed to elicit current concerns, provide information, and facilitate problem-solving in domains relevant to TBI recovery Assessment at one year: Brief Symptom Inventory-Depression subscale (BSI-D), Neurobehavioral Functioning Inventory-Depression subscale, and Mental Health Index-5 (from the Short-Form-36)	2	Control participants developed greater depressive symptom severity from baseline to 1 year than did the treatment group. The treated group reported significantly lower depression symptom severity on outcome measures. For those more depressed at baseline, the treated group demonstrated greater improvement in symptoms than did the controls
Reid-Arndt et al., 2007 [21]	This controlled study evaluated the impact of a <b>telephone referral program</b> on service use and functional outcomes 98 TBI patients included during hospitalization or after discharge: 67 were referred to the Early Referral (ER) program and 31 to the control group (this group received services later in their recovery) Telephone assessments a minimum of five times at varying points during follow-up: social/emotional and vocational functioning, as well as satisfaction with program services	3	The ER group had greater functional limitations than controls upon enrolment. Despite this, at follow-up the ER group evidenced significantly better social integration, emotional well-being and vocational functioning than the control group. Individuals in the ER group did not require/receive more programme resources to achieve these better outcomes
Powell et al., 2002 [22]	RCT comparing an <b>outreach program</b> and controls: (i) Outreach treatment performed by a multidisciplinary rehabilitation mobile team in the community setting. Two sessions a week for 27.3 weeks in average with provision of written information detailing alternative resources. (ii) Control group: only information about existing sources of potential help. Follow-up at 24.8 months in average after allocation Participants: 94 TBI (between 3 months and 20 years post-injury). Outreach treatment ( $n = 48$ ); control group ( $n = 46$ ) Assessment: functional independence (Barthel index), anxiety and depression scale	2	Outreach participants were significantly more likely to show gains on functional independency. Differential improvements were not seen for anxiety or depression
Lee et al., 2014 [23]	Pilot study investigating the feasibility of a combined <b>exercise and self-affirmation intervention (IntenSati)</b> 21 TBI at least 12 months post-injury from an outpatient rehabilitation department in an urban medical center. IntenSati twice a week over the course of 8 weeks ( $n = 12$ ); controls ( $n = 9$ ) received usual care Assessment at three time-points throughout the study and at the end of it using neuropsychological and self-report measures to evaluate participants' cognition and mood	3	The intervention group experienced less depressive symptoms, more positive affect, and had a higher quality of life following the completion of the program. Results associated with cognitive benefits were mixed. The participants tolerated the program well and reported satisfaction with the program

OT: occupational therapy; RCT: randomized controlled trial; TBI: traumatic brain injury.

to implement the acquired knowledge in the management of these patients [19] (level 4).

Four studies focused on the impact post-hospitalization support programs on the mood or well-being of patients with TBI, their closed ones or caregivers [20–23]. In a controlled, randomized, single-blind study (level 2), the authors reported that problem-solving telephone interventions improved depression symptoms in patients with TBI [20]. The program tested included 7 telephone interventions over a 9-month period. In another level 3 controlled study, an improvement of the patients'

emotional well-being was reported in a program of telephone contacts to refer patients to specialized care services in the framework of follow-up after TBI [21]. A study with a control group (level 2) evaluated the relevance of a community-based outreach rehabilitation team made of an occupational therapist, physical therapist, clinical psychologist and a social worker [22]. The group of 48 patients with severe TBI who benefited from this community setting rehabilitation team tended to be more independent, yet no improvement on anxiety and depression was noted. In a controlled study (level 3) based on 21 patients with TBI, a program of physical

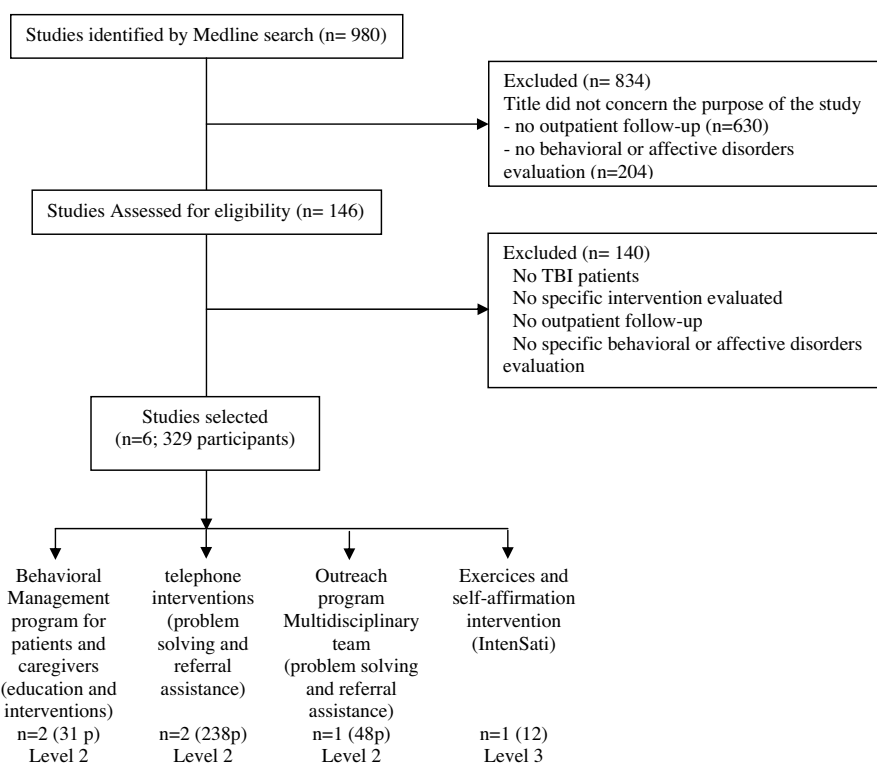


Fig. 1. Flow-chart. Systematic review of relevant articles – iterative levels and final selection. n: number of studies; p: participants.

exercises, consisting of 2 sessions per week, during 8 weeks, showed significant mood improvement in the group of patients who benefited from this program [23].

#### 4. Discussions and recommendations

Based on the results of the analysis of the literature review and the opinion of the SOFMER group participants, practice recommendations are proposed. They concern first the preparation of the discharge then the organization of the follow-up after hospitalization.

##### 4.1. Preparing the hospital discharge

Even if no specific study was found in this literature review, experts consider that the transition phase between the hospital and the return home is often a difficult step for patients and their family. Some so-called “transitional support structures” are interesting but depend on the local health and medicosocial organization. It is recommended to elaborate as early on as possible with the patient and his/her family or appointees, the support project, which includes the life and care projects. The therapeutic alliance is recognized as a key factor for the success of this life project. Among the negative predictive factor of this therapeutic alliance we find, family feuds, divergence of evaluation of the disorders between the family and healthcare professionals [24]. A coordination between hospital and outpatient healthcare teams is recommended with the help of existing services and networks according to the region and the patient's situation: medicosocial support service for disabled adults, at home nursing care, social support service, medicalized structures for outpatients; or structures replacing the home setting when it is not possible to return home: social homes, adapted flats (apartments rented out to

disabled persons via an association, with frequent visits from social workers working in this association). Personal assistance, adapted to each situation, should be anticipated during the hospital stay. In France, these procedures are done in collaboration with the Departmental Home for Disabled Persons grouping within each French department the administrative bodies in charge of allocating human and technical resources to disabled persons and giving out the orientation for discharge to medicosocial structures. It is recommended to ensure that means are fairly allocated at a national level. Home care provided by professional caregivers must be systematically and regularly proposed. The development of mobile outreach teams is recommended to assist the patient's sustainable return home. Preparing the hospital discharge must be based on the September 2004 consensus conference: “Discharge from the hospital and planning the home return of a person with motor and/or neuropsychological disabilities” while respecting the care pathway of TBI patients [13].

##### 4.2. Organizing the follow-up after discharge from the hospital

After inpatient hospitalization, it is recommended, according to individual needs and possibilities, to implement specific outpatient care in a rehabilitation center, private practice rehabilitation sessions as well as follow-up during Physical Medicine and Rehabilitation (PM&R) consultations (see [13]). The integration of patients and their family in a care network is necessary in relationship with the Departmental Home for Disabled Persons and home care systems, specific to each region. Because of the possible evolution of behavioral disorders, a revision of the resources allocated upon discharge can be needed, even during the first year. Furthermore, short-term inpatient care in medicalized structures or homes should be proposed especially for patients with severe disabilities or having behavioral disorders. In France,

this short-term care possibility requires the approval of the Departmental Home for Disabled Persons. In the absence of these types of structures in a region, a short-term hospital stay can be proposed. On top of these general orientations, some recommendations are proposed concerning more specifically the care management of behavioral and affective disorders.

#### 4.2.1. Therapeutic education and individualized program for caregivers

A comprehensive program including a phase of therapeutic education and a phase of individualized help for managing behavioral disorders was reported as effective in a randomized study with a group control [18]. The feasibility of these programs seems good [19]. Nevertheless, these results are based only on two studies (only one with a control group) with small samples. Isolated therapeutic education programs are being developed to support caregivers and patients in the care management of behavioral disorders. An important reminder is that family dysfunctions, anxious and depressive symptoms in family members, especially the spouse or partner, are predictors of behavioral and mood disorders in patients with TBI [7]. Psychological adjustment and marital satisfaction after TBI are better if the patient has a positive perception of his or her spouse's communication skills and an effective attitude towards problems, while excluding the use of avoidance coping strategies [25]. Furthermore, authors reported that family therapy programs could improve the communication between families and professionals [26].

Overall, caregiver management must be one of the objectives and on the long term (grade C). Specific programs targeted for caregivers, including therapeutic education and specific help to manage behavioral disorders must be developed and evaluated (grade B).

#### 4.2.2. Telephone intervention and telemedicine

Regular telephone follow-up interventions can improve patients' mood (grade B). These telephone follow-up can also be useful to refer patients to specialized services, and help with problem-solving. Studies are ongoing to assess the relevance of information support systems and online support but no data were identified regarding the relevance of these approaches on behavioral disorders or mood disorders in the framework of post-hospitalization follow-up of patients with moderate or severe TBI.

Overall, the implementation of a regular telephone follow-up after the hospital discharge can be recommended for the management of mood and behavioral disorders in patients with TBI in addition to the conventional follow-up in outpatient rehabilitation structures and consultations as recommended in the care pathway of TBI patients (grade B) [13].

#### 4.2.3. Pain management

No study was identified on this topic in the review of the literature; one must be particularly vigilant to pain management since pain is correlated to depression and behavioral disorders [5].

#### 4.2.4. Physical activity program

A study with a control group reported the usefulness of regular physical activity on the mood of patients with TBI. Nevertheless, the limited sample of this single study does not allow yet to formulate recommendations.

#### 4.2.5. Holistic rehabilitation programs

No study was identified in the review of the literature. The principle of the therapeutic community, which is one of the component of holistic programs, via meetings with peers (other patients and their family) outside of conventional inpatient hospital stays, promotes the expression of group dynamics,

self-awareness of disorders, integration within the community, social participation and emotional well-being [27]. In patients with moderate to severe acquired brain injury, a holistic rehabilitation program at a distance from the trauma suggests an improvement of the patients' disability self-awareness, yet behavioral or mood disorders were not specifically studied [28].

#### 4.2.6. Coping strategies programs

After TBI, there is a natural progression towards dysfunctional coping, i.e. a tendency to avoid problems and a pessimistic attitude, a feeling of incompetence. Even if no study was found in the analysis of the literature, training programs to implement coping strategies reoriented towards an active, task-oriented coping, seem to improve social integration and quality of life [29]. It is recommended to encourage the development of such programs based specifically on problem-solving strategies and adapted coping skills training.

## 5. Conclusion

Among the important points to remember, the care management of behavioral and affective disorders is primarily based on the application of recommendations regarding the care pathway of patients with TBI [13]. More specific programs such as therapeutic education geared towards caregivers, phone follow-up and physical activity programs seem promising. Very few studies were published and their level of evidence is still low because of their small samples and absence of standardized evaluation measures. Apart from these published data, recommendations are most often based on the opinion of experts. Scientific studies with a solid and adapted methodology are necessary to validate the first results. The development of communication tools and telemedicine opens new perspectives to help patients and their closed ones confronted to behavioral and affective disorders, at the forefront of issues when returning home. The access to a specialized consultation with a psychiatric or psychologist remains difficult and should be facilitated.

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#### Disclosure of interest

The authors declare that they have no competing interest.

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