# Neuropsychological rehabilitation focused on a daily activity in an extremely severe brain-injured patient

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Despite the disabling consequences of severe traumatic brain injury (TBI) in daily life, very few studies focused on the re-education of specific "instrumental activities" in these patients. In this qualitative study, we present an ecological rehabilitation of a patient victim of an extremely severe TBI and presenting severe and diffuse cognitive impairment. The rehabilitation program, focused on the preparation of a vegetable soup, was structured in three steps conjugating various strategies: a phase of acquisition of basic knowledge and procedures, a phase of application to the actual preparation of the soup, and an adaptation phase devoted to making the activity a purposeful part of the patient's life. Results showed that it is possible to increase the abilities of severely impaired patients in a daily task, as well as their self-awareness, by means of an individualized, contextualized and intensive rehabilitation. However, several limitations must be considered.

Keywords: rehabilitation, severe traumatic brain injury, severe cognitive deficits, daily life, self-awareness deficit

Malgré les effets invalidants qu'un traumatisme crânien sévère (TCC) peut avoir sur la vie quotidienne, très peu d'études ont porté sur la rééducation « d'activités instrumentales » chez ces patients. Dans cette étude qualitative, nous présentons la prise en charge d'un patient présentant des troubles cognitifs sévères et diffus à la suite d'un TCC très sévère. Le programme d'intervention, visant la réalisation d'une soupe aux légumes, a été structuré en 3 étapes conjuguant de multiples stratégies : une phase d'acquisition de connaissances et de procédures de base, une phase d'application à la réalisation de la soupe et une phase d'adaptation visant une implémentation de l'activité dans le quotidien du patient. Les résultats montrent qu'il est possible d'améliorer les capacités de patients traumatisés crâniens sévères dans une activité spécifique de vie quotidienne, ainsi que leur anosognosie, au moyen d'une rééducation individualisée, en contexte réel, et intensive. Plusieurs limitations doivent toutefois être prises en compte.

Mots clés : rééducation, traumatisme crânio-cérébral sévère, troubles cognitifs sévères, vie quotidienne, anosognosie

Traumatic brain injury (TBI) is a major medical, public health, and societal problem worldwide. It covers a wide range of severity. The most common severity classification is by the Glasgow coma scale, considering a score of 13-15 as mild, 9-12 as moderate, and 3-8 as severe (Jennett, 1996). The duration of post-traumatic amnesia (PTA) is another indicator of TBI severity. According to the Jennett and Teasdale classification (1981), the TBI is considered to be mild with a PTA of less than 1 hour, moderate with a PTA of 1 to 24 hours, severe with a PTA of 1-7 days, and extremely severe with a PTA superior to 4 weeks. Among all trauma-related injuries, TBI represents the greatest cause of mortality and functional disability, with most long-term disability caused by moderate to severe injury (Ponsford, Draper, & Schonberger, 2008; Rubiano, Carney, Chesnut, & Puyana, 2015; Zaloshnja, Miller, Langlois, & Selassie, 2008). The incidence of severe TBI is estimated to be 73 cases per 100,000 people, equating approximatively 5.48 million people affected to (Dewan et al., 2018). A growing international literature agrees on the permanent functional limitations in victims of severe TBI (Andelic et al., 2009; Dikmen, Machamer, Powell, & Temkin, 2003; Skandsen, Nilsen, Fredriksli, & Vik, 2008). Despite fairly good physical recovery, these patients often sustain long term cognitive and socio-behavioural impairment which may have a profound impact on their capacity for independent living and community integration. They then appear to be unable of forming

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or sustaining relationships, returning to study or employment, and taking part in leisure activities or carrying out ordinary daily activities (Lillie et al., 2010). Basic activities of daily living (e.g., eating, toileting, dressing etc.) can be recovered, but more complex activities, commonly known as instrumental activities of daily life (IADLs), such as cooking, shopping, financial management etc., usually need external supervision and can't be carried out autonomously (Colantonio et al., 2004; Kozlowski, Pollez, Thevenon, Dhellemmes, & Rousseau, 2002; Quintard et al., 2002).

A first element to be considered is the extent of cognitive impairment and its degree of severity. Executive dysfunction is, in particular, a frequent consequence of severe brain concussion as well as a primary cause of disability in everyday life (Hanks, Rapport, Millis, & Deshpande, 1999; Jourdan et al., 2013; Tate et al., 2014; Worthington & Waller, 2009). Executive difficulties (including impaired planning and problem solving, goal-directed behaviour, inhibition, abstract thinking and mental flexibility), resulting from (pre)frontal lesions or more widespread injuries affecting these circuits (Alvarez & Emory, 2006; Heyder, Suchan, & Daum, 2004; Stuss, 2011), can in fact undermine the capacity to complete daily tasks, especially if they are unfamiliar or multitasking. Often associated with executive impairment, attention (Caron et al., 2018; Dymowski, Owens, Ponsford, & Willmott, 2015; Mathias & Wheaton, 2007) and memory deficits (Caron et al., 2018; Velikonja et al., 2014; Wright, Schmitter-Edgecombe, & Woo, 2010) can also have a deep impact in autonomous living. Attention deficits can generate distractibility, slowness and fatigue. Memory impairment may have a significant impact by compromising, for example, the acquisition of new information and abilities which are essential to everyday life. Patients with memory deficits may also have difficulty to spontaneously remember to engage in a goal-directed activity. A second complication consists in the high prevalence of emotional and behavioural disturbances following severe TBI (see Stéfan, Mathé, & SOFMER group, 2016 for a review). Evidences show that more than one third of individuals with moderate to severe TBI experience behavioural, affective or psychological changes after the injury (Babbage et al., 2011; Brooks, Campsie, Symington, Beattie, & McKinlay, 1987; Tateno, Jorge, & Robinson, 2003). Manifestations can be quite different such as impulsivity, lowered frustration tolerance, irritability or reduced initiative, apathy, affective disorders etc. (Ciurli, Formisano, Bivona, Cantagallo, & Angelelli, 2011). In about two thirds of patients, these disorders are still present several years posttrauma (Brooks et al., 1987). Indeed, if cognitive deficits typically show improvement over time, challenging behaviours tend to persist (Koponen et al., 2002; Masson et al., 1996) or even get gradually worse, in association with multiple factors such as changes in familiar dynamics, autonomy loss or neurological, personal and environmental factors (Arnould, Dromer, Rochat, Van der Linden, & Azouvi, 2016). They thus represent not only a main problem for social reintegration (Milders, Fuchs, & Crawford, 2003), but are also a prior cause of the ineffectiveness of much cognitive rehabilitation (Cattelani, Zettin, & Zoccolotti, 2010).

limitation, besides cognitive Another and behavioural deficits, is the lack of self-awareness often shown by patients with frontal lesions (Toglia & Kirk, 2000). Mostly associated with executive dysfunction (Ownsworth & Fleming, 2005) awareness deficits have a strong impact on functional outcomes, affecting processes of on-line monitoring of the current task and error recognition. Moreover, individuals with less insight or awareness may have difficulties in setting realistic goals for rehabilitation, will have less motivation to engage fully in the treatment and are less likely to actively participate in rehabilitation (Huffort, Williams, Malec, & Cravotta, 2012; Tate et al., 2014).

Finally, some premorbid personality factors such as a history of abuse of alcohol or drugs are relatively common in survivors of severe TBI (Beaulieu-Bonneau et al., 2017; Bryce, Spitz, & Ponsford, 2015) and are therefore another significant limitation to the setting and success of a rehabilitation program. Clinicians then face the difficulty of selecting with the patient key activities that are relevant and motivating for him, as well as the possibility of relapse with all its consequences.

Despite the disabling consequences of severe brain injury, the literature about the rehabilitation of this clinical population is very poor and very few studies have yet focused on the re-education of specific IADLs. Most of the studies tailoring daily activities have been conducted on subjects with mild to moderate cognitive deficits, mostly in the domain of executive functions (see Boelen, Spikman, & Fasotti, 2011 for a review).

Clinical evidence-based practice guidelines have been provided to assist clinicians in the cognitive rehabilitation of severe TBI. The authors stress that "cognitive assessment and rehabilitation should be tailored to the patient's neuropsychological profile, premorbid cognitive characteristics, and goals for life activities and participation" (Bayley et al., 2014, p. 290).

In the domain of executive dysfunction, evidencebased recommendations for TBI patients encourage at first instance the use of metacognitive strategies applied to everyday life problems (Tate et al., 2014). For instance, Goal Management Training (GMT; Robertson, 1996) was proven to be beneficial for patients with mild to moderate cognitive deficits post-TBI, showing goal-directed behaviour difficulties in daily life activities (Grant, Ponsford, & Bennet, 2012; Krasny-Pacini, Chevignard & Evans, 2014; McPherson, Kayes, & Weatherall, 2009). Based on Ducan's theory of "goal neglect" (Duncan, Emslie, Williams, Johnson, & Freer, 1996), the GMT is a staged protocol aimed at helping dysexecutive patients to better structure their activities by stopping their ongoing behaviour to define a hierarchy of goals and sub-goals and monitor their performances. As all metacognitive strategies, this rehabilitation technique can be effective especially with "patients that are aware of their need to use a strategy and can identify contexts in which the strategy could be use" (Tate et al., 2014, p.348). The learning of the procedure and its spontaneous application in real life appear to be too difficult to acquire for people with severe and extensive cognitive deficits, and with impaired selfawareness. Some principles can be used effectively though, and any attempt at modifying the procedure can be made to render it more accessible to these patients.

When executive impairment coexists with other severe cognitive deficits (e. g. memory impairment), external devices, such as paging systems (Wilson, Emslie, Quirk, & Evans, 2001) or alarms (Zermatten, Rochat, Manolov, & Van der Linden, 2018), might be an appropriate choice to address planning and organizational problems. For example, Zermatten et al. (2018) have shown the efficacy of an external cueing system to create and trigger intention in a patient presenting severe and diffuse cognitive impairment due to a cerebrovascular disease. Modifications of the environment and of the task (e.g., reduce distractions, modify the speed or the amount of information to be processed, give material in a written form etc.) may be used to limit the impact of attentional deficits and facilitate execution of the task (Ponsford et al., 2014). Environmental supports and reminders are recommended for TBI patients who have severe memory impairment (Velikonja et al., 2014). While working on practical tasks and learning new skills or information, there appears to be general support for constraining errors. An errorless learning approach (to avoid implicit reinforcement of the mistake) proved to be significantly effective (Kessels & Haan, 2003), and is a core principle of any intervention program with severe amnesic patients, often paired with a spaced retrieval (recall the information at gradually increasing intervals of time) or a vanishing cues (progressively reduce cue information across learning trials) methods.

When working with TBI patients who have impaired self-awareness, the guidelines oriented mostly towards interventions aimed to increase this aspect (Tate et al., 2014). Among all approaches described in the literature, the authors recommend the use of direct corrective feedback (verbal, audio-visual, experiential). This feedback should be delivered within the context of a rehabilitation program specifically addressing self-awareness deficits. Some studies using corrective feedbacks in conjunction with other methods within the context of functional daily life activities have shown good global improvement in task-specific self-awareness, self-regulation (error correction) and functional outcome (Fleming, Lucas, & Lightbody, 2006; Goverover, Johnston, Toglia, & DeLuca, 2007; Ownsworth, Fleming, Desbois, Strong, & Kuipers, 2006).

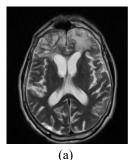
Finally, behavioural problems must be monitored constantly and directly, and tailored to maintain the patient's motivation and his adherence to the treatment. With patients having poor cognitive and self-control abilities, contextual adaptation (for example, only offer male therapist to a patient with sexual disinhibition) should be applied. If contextual changes are insufficient to reduce the problem, it may be necessary to consider approaches, such as contingency management, based on applied behavioural analysis (Ponsford, 2013; Wood & Alderman, 2011). Behavioural modification procedures are designed either to increase the probability of desirable behaviours by a reward or to decrease the probability of undesirable behaviours. Positive reinforcement is commonly provided by a token economy system: a token is delivered immediately after a desirable behaviour and can then be used to get something coveted (Ayllon & Azrin, 1968). When taking into account all the limitations listed at the beginning of the introduction (the extent and the severity of cognitive deficits, the high prevalence of emotional and behavioural disturbances, the frequent lack of self-awareness and a possible history of alcohol or drugs abuse) as well as the factors which may contribute to difficulties in a specific daily activity, it appears evident that there is a clear need to adopt an individualized and integrative approach, which includes multiple strategies acting at different levels.

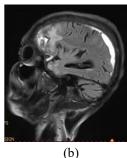
Considering that further ecological study is required for severe TBI patients, in this manuscript we describe an individualized and multidimensional intervention program aimed to increase performances on a specific daily task in EG, a patient with severe brain injury living in a sheltered home and presenting severe and diffuse cognitive impairment. More specifically, our main purpose was to improve EG's functional autonomy in preparing a vegetable soup and to introduce this activity into his daily life. Moreover, we hypothesized that an occupationalbased intervention could improve EG's awareness of his daily difficulties.

#### **Case report**

We present the case of EG, a man in his mid-50s who sustained an extremely severe TBI (TBI with PTA longer than one month; Jennett & Teasdale, 1981). Premorbid, he worked as a house painter and had a history of alcohol abuse. He was divorced and lived with his mother. In March 2014, due to excessive alcohol consumption, EG fell, striking the occipital region of his head; this caused severe TBI with a loss of consciousness for about five minutes. A Glasgow Coma Scale score of 11/15 was recorded on the arrival of the ambulance, with successive fluctuations up to 12/15. The duration of PTA evaluated prospectively with the Julia Farr Post Traumatic Amnesia Scale (Forrester & Geffen, 1995), extended to 3.5 months. An initial computed tomographic scan reported right temporo-parietal and left occipito-temporal skull fractures and severe bilateral haemorrhages; a right craniotomy was performed to evacuate a frontal subdural hematoma. After a month of acute hospitalization, the patient was transferred to a specialized brain injury rehabilitation unit (the CRR-Sion) for further treatment and intensive rehabilitation. A two months later postinjury, magnetic resonance imaging (MRI) revealed extensive frontal bilateral lesions, as well as bilateral temporal contusions, a small intra-parenchymal haemorrhagic contusion in the right posterior parietal lobe, unspecific lesions of the white matter and occipital microbleeds (Figure 1).

Consistent with the widespread brain damage, EG's clinical profile was characterized by a global cognitive impairment with associated behavioural disorders and severe anosognosia. Daily neuropsychological rehabilitation was provided during





*Figure 1*. MRI scan 2 months post-injury (a) sagittal T2w (b) transversal T2w

his 4-month stay in hospital. At the time of the study, EG had been dismissed from the hospital and was living in a sheltered home. He couldn't return to work and attended outpatients' neuropsychological rehabilitation twice a week.

# Clinical course and daily functioning

During his stay at the CRR-Sion, EG evolved positively, emerging from post-traumatic amnesia and showing progressive improvement in the areas of mobility, cognition and behaviour. A detailed neuropsychological assessment was carried out at eight months post-injury (cf. Table 1).

EG was well-oriented in time and space. Insight and awareness were very poor; EG didn't have any complaints and reported no difficulties in daily activities, but test results reflected serious global cognitive impairment. EG's ability to retain and recall new information was seriously lacking and his retrograde memory was altered for recent events. Implicit memory was preserved but semantic memory was impaired. Executive functions were also badly impaired, with deficits mostly in inhibition, planning, incitation and problem solving and, to a lesser extent, in flexibility, working memory and abstraction. EG was precipitated, perseverative and disinhibited. His performances in an emotion recognition test were under-average and his attentional functions were moderately impaired. His oral expression was fluent and functional but characterized by anomia, paraphasias, and speech disorganization. A mild comprehension deficit was also observed. Such cognitive deficits had a significant impact on EG's daily autonomy. His reference caregiver in the sheltered home reported severe difficulties in anticipating, planning and carrying out daily activities. EG needed help for the most basic and instrumental daily activities (e.g., taking shower, ordering cloths, taking medicines). He helped preparing soup, doing the washing up and setting the table, but was easily distracted and never finished an action. He never took initiative and needed constantly to be reminded what to do. If left alone, EG could spend the whole day watching television and could react violently when forced to do something else. His referents reported frequent verbal outbursts which, in their opinion, were easily manageable. EG's irritability was brought about especially by conditions of fatigue, frustration or unforeseen situations. Nevertheless, EG was wellregarded by the other residents; he appreciated having some responsibilities and gladly participated in community activities. In December 2014, he started doing voluntary work in a centre for TBI patients.

## Table 1

# Summary of EG's neuropsychological assessment

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*Note.* RBMT = *Rivermead Behavioural Memory Test* – *Third Edition.* <sup>a</sup>Kaplan, Goodglass, &Weintraub (1983); <sup>b</sup> De Renzi &Vignolo (1962); <sup>c</sup>GREFEX (2001); <sup>d</sup>Poppelreuter (1917); <sup>c</sup>Gauthier, Dehaut, and Joanette (1989); <sup>f</sup>Wechsler (2008); <sup>g</sup>CHUV version (1985); <sup>h</sup>Dubois et al. (2002); <sup>i</sup>Wilson et al. (2008); <sup>j</sup>Gollin (1960); <sup>k</sup>Howard & Patterson (1992); <sup>i</sup>Thuillard & Assal (1991); <sup>m</sup>GREFEX (2001); <sup>n</sup>CHUV version (1987); <sup>o</sup>Goebel, Fischer, Ferstl, & Mehdon, (2009); <sup>j</sup>Wilson et al. (1996); <sup>q</sup>Dubois, Slachevsky, Litvan, & Pillon (2000); <sup>i</sup>Brickenkamp & <sup>i</sup>Cillard & Steine (1987); <sup>i</sup>Cillard Zillmer (1998); <sup>s</sup>Zimmermann & Fimm (2009); <sup>t</sup>Ekman & Friesen (1976).

\*Most of the tests are matched by age and by education. \*\*Impaired = when EG's performance is inferior to M -1.65 (SD), is below percentile 5 or is below the borderline score.

#### Method

# **Choice of intervention**

After a first intervention (not presented here) targeting EG's autonomy for his personal care and daily organization, we tried to identify an activity with him and his referents, that he would enjoy and would be useful for his personal independence, but EG actually showed little interest in working on any daily activities. His relatives described him as a person who had never had many interests except for his job and going to the pubs. The sole desire EG manifested, was to get back his house painter's job. But no painting activity was available in the workshop. As EG had been assigned to the cooking unit, we opted for this solution. In fact, a cooking activity seemed to be an rehabilitation objective for several appropriate reasons. First, cooking is a means of addressing the most basic needs of nutrition and health. Second, we thought that involving EG in doing something regarding taking care of the other residents would improve his feeling of self-efficacy and initiativetaking. Finally, the complexity of the task made it possible to target the difficulties of initiation, organization and self-monitoring observed in many daily activities. Considering EG's premorbid level of cooking expertise, as well as his serious cognitive problems, we decided to restrict the intervention to a sole and simple recipe, which was familiar to him: a vegetable soup (the only meal prepared in the sheltered house and for which EG already offered his help). We presented this option to EG who manifested his interest and agreement.

### **Ecological assessment**

As the sole cognitive evaluation was insufficient to predict EG's performances in a real cooking setting, we carried out an ecological assessment, consisting of preparing a vegetable soup (based on the specific recipe of the sheltered home). Immediate observation and further detailed analysis of EG's performances showed serious difficulties, which compromised the autonomous realization of the task. One main problem consisted of insufficient checking (of the written recipe and of his own actions) leading to many errors. EG was easily distracted and was often on the verge of abandoning the task. Numerous impulsive and irritable commentaries, frequent commenting and appeals for help, were also observed. Finally, EG had difficulties in recognizing and selecting the right ingredients, and in using the mixer.

#### **Objectives and hypothesis**

The rehabilitation program was aimed at improving EG's functional autonomy in preparing soup and introducing this activity into his daily life. Based on the results of the ecological assessment, the preliminary stages consisted of: 1) learning how to use the mixer; 2) improving recognition of unknown ingredients; and 3) improving checking by consulting a written script. Considering the extent of EG's cognitive impairment, we did not expect him to interiorize the recipe or to be completely independent: we considered that the most important for him was to be able to refer to the written recipe and to act with as few errors and help as possible. Furthermore, we aimed to include this activity in EG's daily life, so he could prepare the soup for the other residents twice a week. Finally, we formulated the hypothesis that EG's awareness of his difficulties could be improved by direct confrontation with his difficulties in a real setting, discussion with the clinician and external feedbacks during the intervention.

#### Design

We set up an intervention protocol consisting of pre-intervention three phases: assessment, rehabilitation, and post-intervention assessment (cf. Figure 2). The rehabilitation program lasted 32 sessions and was administered in up to 4 sessions a week, during a period of 2.5 months. Each session lasted from 45 to 90 minutes. Three stages were defined: 1) acquisition of basic knowledge and procedures (learning the use of the mixer, improving recognition of the ingredients, learning a checking routine); 2) application of these acquisitions for the actual realization of the soup; 3) adaptation: making the activity a purposeful part of the patient's life. The number of sessions for each step of the acquisition phase was not pre-established, but rather depended on

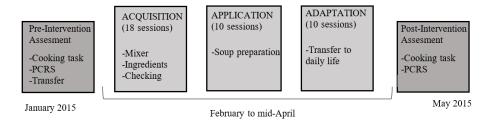


Figure 2. Graphical representation of the intervention

EG's progress. The application phase was limited to 10 sessions. The interventions took place in different locations depending on the phase in the program: in the neuropsychological office, but also in the sheltered house and in the sheltered workshop (in order to facilitate the transfer of EG's acquisitions to his daily context).

## Procedure

General framework. Some general strategies have been employed during the whole intervention in order to limit the impact of EG's cognitive deficits and sustain his personal motivation. Firstly, to contour the influence of EG's memory deficits, we implemented a diary with information regarding the rehabilitation objectives and the results obtained in each session. The systematic consultation and updating of this diary were also conceived to increase EG's awareness of his personal difficulties and to sustain his work and personal motivation. With the same motivational purpose, a reward system inspired by the Token Economy Techniques (Ayllon & Azrin, 1968) was scheduled. During the whole rehabilitation program, several meetings with the people in charge of the sheltered house and EG's took place. Finally, to limit the impact of executive and attentional deficits, manipulation of the environment and of the task represented a central part of every phase of the intervention.

**Phase of acquisition.** This first phase took place three times a week, over a six weeks period. Initially, the mixer was worked in parallel with the recognition of the ingredients. Once EG had acquired these competences, we worked on improving checking.

*Learning the use of the mixer.* A learning method combining vanishing cues technique with errorless learning principles was employed to train EG to the use of the mixer. A sequence of seven-steps is required for proper use of this kitchen utensil. Initially EG was guided (verbally and physically) through the whole task but later external assistance was gradually reduced: EG was guided through all the steps in the sequence except the last one, where he was required to perform without help, then the last two steps of the chain were omitted and so forth, until he managed to do the whole task on his own. In order to reduce the probability of errors, EG was encouraged not to act if he was unsure of the following step to perform. If an error occurred, the correct action was shown by the therapist and the procedure was taken back to the last successful phase. The intervention was administered twice a week. Each session included five learning trials. The first sessions took place in the workshop's kitchen. A generalization to EG's daily context was considered when he succeeded in realizing five trials in one session. The number of sessions devoted to this phase of intervention was determined by the following criterion: EG should correctly execute five trials for two consecutive sessions. The long-term maintaining of this acquisition was evaluated by the following observations in the cooking setting.

Improving recognition of ingredients. Parallel to the mixer, we worked on improving EG's recognition of the ingredients. In order to have a reference point for measuring EG's progress in this specific acquisition task, two additional baselines (different from the pre-intervention cooking task assessment) were carried out. These baselines consisted of a designation task. The set of ingredients was placed on the table. EG was shown one name at a time, and he was asked to point to the corresponding ingredient. The set included the eight ingredients in the recipe, as well as two distractors (which EG was not questioned about): these were added intentionally to limit the probability of random answers. This phase of testing provided further evidence that EG was unable to recognize four ingredients. The same procedure was also used at the beginning of each session in order to measure the progress in learning. Immediately after the testing phase, a learning method, combining vanishing cues and spacing reversal in an errorless approach, was brought in three times a week. Only two ingredients were used at first; the other two were only introduced once the previous ones were recognized in the next session. EG was given the ingredients and a card with their names written on it. He was asked to read the names and to copy them down on a piece of paper. Then, the letters were removed one by one, and each time EG was asked to complete the word. Once he managed to write the names without any cues, a designation task was proposed, using a spaced-retrieval approach. The shortest interval lasted 30 seconds, and the longest 16 minutes. EG was asked not to guess. If he responded incorrectly, the right ingredient was pointed to by the therapist, and the interval was halved for the next test. The vanishing-cues technique was proposed only for the items which were not recognized at the beginning of the session. To avoid inhibition processes, the spacing recall technique was always performed for the four problematic ingredients. The learning criterion was set at 100% correct ingredients recognition for three consecutive sessions. A follow-up assessment was scheduled for two weeks later.

*Improving the checking routine.* In this phase, a simplified form of GMT (Robertson, 1996) was applied to pencil-and-paper tasks, in order to improve the checking processes during task execution and to reduce distractions and commentaries. The program was adapted to EG's difficulties. Given his anosognosia, the psycho-educational phase was limited to an explanation of GMT's principles applied

to the preparation of soup. Particular importance was attributed to the first step in the GMT procedure; in this context, the therapist agreed on a phrase with EG ("STOP sheet") which could be applied both to the pencil-and-paper exercises and to the use of the cooking recipes. Two types of tasks were proposed. In the first two sessions, EG was presented with simple target cancellation tasks. In the following sessions, he worked on more complex exercises similar to those ones used by Levine et al. (2000). EG was presented with a paragraph of text and a list of instructions in which he was asked to find out (circling, underling or crossing out) words corresponding to a specific criterion. The instructions were given in the written form, on a separate sheet. Each instruction was followed by another one which specifically asked to check what he had just done. The instruction sheet was placed in a folder cut into strips, so that only one instruction could be read at the time, while the others were hidden. Before starting the exercise, the therapist made sure EG understood all the instructions. Then, EG had to say: "STOP sheet" and turn over one strip at a time to carry out the corresponding instruction. The last instruction always consisted in a check of the whole exercise. Further, to increase EG's monitoring of his verbalization, and to promote his concentration on the task, acoustic feedback was given by the therapist at each commentary. The procedure terminated once EG reached the following criterion: < 5 % checking errors and  $\leq 1$  commentary.

**Phase of application.** Ten sessions, spread over four weeks, had been devoted to the preparation of the soup. Two sessions per week took place at the workshops and one at the sheltered house.

The GMT principles that EG had previously learned were applied to encourage his concentration on the task and the verification of each step. The recipe was written on a plastic sheet and inserted in a support, such as the one used for the pencil-and-paper exercises, and used in the same way. The activity was broken down into several parts which were carried out separately. The first session was devoted to the preparation of the ingredients. EG had to select the ingredients from distractors and to place them on a cutting board. At first, he had a sheet with an explanation of every action to be performed. Then, the actual recipe was provided and EG was asked to use an indelible marker to cross out the name of each ingredient moved on the cutting board. The same procedure was used for the "peel" and "cut" the vegetables step (second session). Two sessions (3 and 4) were envisaged for the first half of the recipe, in order to repeat and reinforce the strategies just learned and to structure them in a sequence. The fifth session focused on the second half of the recipe. In this context, EG learned to use an alarm clock to control the cooking time. Finally, five sessions were used to work on the whole activity and to promote a proceduralization of the task. In general, when EG made an error, the therapist waited a few seconds to give him the opportunity to self-correct his error. When self-correction did not occur, a general prompt was provided. If this was ineffective, EG received a more specific prompt.

**Phase of adaptation.** The final goal consisted of introducing the cooking activity in EG's daily life twice a week. To reach this objective, it was decided to introduce an acoustic alert system.

Unfortunately, EG's motivation for this activity gradually decreased (see the Discussion's subsection entitled *Behavioural problems*) and when we arrived at this phase, our objective seemed no longer pertinent. As in the end, we decided to abandon the procedure, we won't describe it here.

# **Outcome measures**

**Cooking activity.** In order to measure the efficacy of the intervention on soup preparation, an ecological assessment was carried out. As the intervention was to focus a sole recipe, the pre and post-intervention assessments consisted in exactly the same activity. The observation took place in the kitchen of the sheltered house. Before starting, the examiner took the time to explain each step of the recipe to EG. The written recipe was always available. Vegetables were arranged on the table, while EG had to look for the utensils which were in their usual place. Some items (objects and ingredients) unnecessary for this particular activity were placed around the kitchen as potentials distractors. EG was encouraged to perform the task alone; the examiner only intervened when there was a potentially dangerous situation or if EG was completely stuck during an action. Based on Chevignard et al. (2000), errors were first classified on a descriptive level in five types : omissions (any action or sequence of actions necessary to reach the goal that are omitted or incompletely performed), additions (any action or sequence of actions unnecessary for the completion of the task), inversion-substitutions (any action performed that is not part of the appropriate temporal sequence, or any object that is misused or inappropriate to the sub-goal), estimation errors (poor estimation of the quantity, size, space, or time), and comments or questions. The same errors were then classified according to the cognitive mechanisms underlying each error: control errors (inefficient monitoring of action), context neglect (failure to respect the instructions or the environment), environmental adherence (inappropriate action induced by the presence of an object), purposeless actions and displacements (a behavioural sequence not

contributing to goal achievement), dependency (any question regarding how to perform an action), and behavioural disorders (any socially inappropriate or dangerous behaviour). Moreover, based on EG's specific difficulties, further significant parameters were calculated: distractibility (number of times that EG was distracted by an external stimulation causing interruption of the task), recognition errors (each time EG took a wrong ingredient instead of the correct one, or that he asked the examiner for the name of an ingredient), utensil utilization errors (primarily the mixer) and the number of interventions on the part of the examiner. The activity was videotaped, and the evaluation was carried out independently by two examiners; the rating discrepancies were resolved through discussion.

**Transfer to daily life.** Once chose the days in which EG could prepare the soup and introduced them in his daily planning, we asked the responsible of the sheltered home (Ms G) to register the number of times EG realized the task, with or without external incitation, for a period of three consecutive weeks. Moreover, Ms G was encouraged to estimate the amount of help needed from EG using a five-point Likert scale (from 1 = none to 5 = maximum).

**Self-awareness.** The effect of the re-education on EG's awareness of his daily difficulties was evaluated with the *Patient Competency Rating Scale* (PCRS; Prigatano et al., 1986). The PCR is a 30-items instrument which asks the subject to rank his/her ability to perform a large variety of daily activities, using a five-point scale (from  $1 = can't \ do \ to \ 5 = can \ do \ with \ easy$ ). The subject's responses are then contrasted with those of a significant-other who rates the subject on the identical items. A positive discrepancy score between the self and significant-

other versions indicate that the patient has overestimated his abilities. The PCRS has sound psychometric properties, with good internal consistency (patients: Cronbach's  $\alpha = .91$ ; relatives: Cronbach's  $\alpha = .93$ ), interrater (r = .92) and test-rest reliability (patients: r = .97; relatives: r = .92) (Fleming, Strong, & Ashton, 1998; Fordyce & Rouche, 1986; Prigatano, Altman, & O'Brien, 1990). Moderate convergent validity was also found between the PCRS and the Awareness Questionnaire (patients: r = .50; relatives: r = .62; Sherer, 2003).

## Results

#### **Preliminary results**

This section addresses EG's results for the three preliminary stages (phase of acquisition: 1) learning how to use the mixer; 2) improving recognition of unknown ingredients; and 3) improving checking).

#### Phase of acquisition.

Learning the use of the mixer. Six sessions were necessary for EG to learn the correct use of the mixer (cf. Figure 3). In the first session, he systematically omitted the first step (turning off the stove). Delayed verbal recall of such steps was proposed, thus allowing correct execution of the two last of five trials. This situation was maintained in the next sessions. Three sessions in the workshops were necessary before envisaging a generalization to EG's daily context. A slight decrease in his performance was observed here, mostly caused by the less structured context which affected EG's collaboration and concentration. In general, EG easily got nervous at having to repeat the same thing several times over and he tended to stop the activity half-way through.

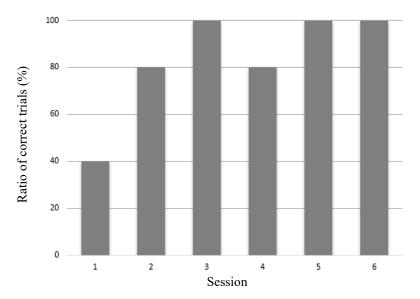
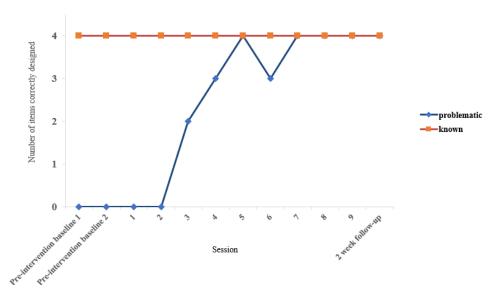


Figure 3. Bar chart highlighting the ratios of correct trials performed by EG in each session

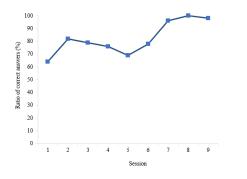
*Improving EG's recognition of the ingredients.* Training was demanding because of EG's fluctuating collaboration and frequent outburst which limited his concentration and contributed to his making errors during the spaced retrieval phase. Two sessions were cancelled. Nevertheless, progress was favourable (cf. Figure 4). The results indicated improvement in distinguishing the problematic ingredients and stability in recognizing the four items he was familiar with. The learning criterion was reached in nine sessions. Performance remained stable in the twoweek follow-up.

*Improving the checking routine.* In the first exercises, EG showed great difficulty in using external support: he was impulsive, overlooked the checking steps and systematically omitted the last instruction.

Progressively, he began to master the help procedure and became aware of the advantages of the checking steps. He spontaneously started to adopt various checking strategies which resulted in fewer errors (cf. Figure 5). Moreover, he rapidly learned to focus on the task and to control his commentaries (cf. Figure 6). EG's commentary increased slightly when he faced the more difficult exercises, but he mastered them quickly nevertheless. The training phase lasted nine sessions. In conclusion, his performances were not EG was often hesitant and some errors optimal. persisted due to his impulsivity and to inaccurate reading of the instructions. Furthermore, he had great difficulty in learning the sentence "STOP sheet" which he produced only with external prompt. EG appreciated this phase, he was collaborative and interested in his results.



*Figure 4.* Number of items correctly designed for the whole set of 8 aliments (4 problematics and 4 already known) at 2 pre-intervention baselines, 9 intervention sessions and 2-week follow-up



8 5 5 5 6 5 1 0 1 2 3 4 5 6 7 6 5 1 1 2 3 4 5 6 7 8 9 Session

*Figure 5*. Mean proportion of correct answers in each training session

*Figure 6*. Number of commentaries during each training session

Phase of application. In the first sessions of this phase, EG had considerable difficulty in applying what he had learned previously to the real cooking setting. In the first session, he appeared confused and committed several errors in selecting the ingredients. Even if all the ingredients were recognized correctly in the following session, some omissions persisted due to inefficient checking processes. EG did not spontaneously cross out the names of the ingredients and, when prompted, he was disappointed and acted in a disorganized manner. EG had also problems in using the mixer the first time he used it again; a recall of the steps in its use was then carried out. Generally, EG was reluctant to use external support and had to be encouraged to read the recipe. With time, he learned to consult the written script regularly and to complete each step in the right order. He also learned to cut and wash the vegetables and to use the alarm clock without being prompted. As far as his behaviour was concerned, considerable irritability persisted, with frequent outbursts. He became more disinhibited, with repeated proposals of a sexual nature and recurring attempts at closer contact. The most important problems occurred during the sessions in the sheltered home where noises and distracters made EG easily irritable. In addition, he became progressively demotivated. He recognized the session was useful and, at the end, he was said to be satisfied at the success of the soup. However, he was not interested enough in it to apply it to his daily life.

# **Outcome measures**

**Cooking task.** Table 2 shows an improvement in EG's performance as regards all the criteria examined.

On post-intervention evaluation, EG committed fewer estimation errors, additions and omissions; and no further inversion errors were observed. The number of commentaries and questions also decreased. EG appeared more independent, addressed the examiner less and asked fewer questions. He also kept to the written instructions better, showed fewer signs of perplexity and verified his actions in a more systematic way. However, some errors persisted in the sequences of actions that EG had carried out automatically and for which he did not read the script. This explains the only error he made when using the mixer (forgetting to turn off the stove). He had no further problems in identifying and selecting the ingredients. Significant improvement was also observed as regards his attention level. Despite the numerous distracters, EG managed to stay focused on the task in hand and, if he was momentarily distracted, he managed to return to his work without being prompted. Despite this progress, EG was not completely independent; some errors were always present and the number of commentaries and inappropriate behaviour (irritability and impulsiveness) was still high, even if it had decreased.

**Transfer to daily life.** As mentioned above (subsection *Phase of adaptation* in the *Method* section), the final objective of the rehabilitation did not seem pertinent anymore, so we decided to terminate it prematurely.

**Self-awareness.** On the PCRS, the comparison between the pre-intervention scores (significant other = 81; self = 131) and the post-intervention scores (significant other = 82; self = 100) indicated a

### Table 2

Results of the cooking task:	total number of errors,	, and number of errors	for each type, before and	d after the rehabilitation.

	Before	After		Before	After
Descriptive analysis			Neuropsychological analysis		
Estimation errors	5	2	Control errors	9	3
Additions	6	1	Context neglect	17	13
Omissions	13	5	Environmental adherence	1	1
Inversions-substitutions	2	0	Purposeless actions	10	3
Commentary-questions	163	88	Dependency	63	18
Total	189	96	Behavioural disorders	61	44
External interventions	42	10	Total	161	82
Distractibility	12	2	Utensil utilization errors	6	1
			<b>Recognition errors</b>	8	0

decrease in the level of discrepancy between the ratings. The 30-point decrease occurred mainly as a result of EG's rating his skill level lower (Ms G's scores remained globally stable). The kitchen activity, judged as easy to accomplish before the intervention, was then evaluated as *very difficult*. In a similar way, EG changed his judgment for other domains, more or less related to the intervention. Nevertheless, his estimation of his difficulties remained inferior to that of Ms G's. Clinically, EG seemed more capable of recognizing his errors and appreciating the quality of his performance. He was more inclined to talk about his behavioural problems and to furnish his own explanations.

# Discussion

The aim of this qualitative study was to investigate effectiveness personalized the of а and *multidimensional* intervention improve to the autonomy of an extremely severe traumatic braininjured patient (EG) in a specific instrumental daily activity. This program was part of a more global project, aimed to promote EG's autonomy and to give him some responsibilities in the sheltered home. Based on a preliminary detailed evaluation, and taking into consideration the peculiarities of this clinical population, we designed an intervention focused on a specific activity (preparing a vegetable soup), structured in several steps and conjugating various strategies. The results globally show a positive evolution, even though the final goal was not reached.

# Acquisition of basic knowledge and procedures

In particular, despite his severe cognitive impairment, EG appeared to be able to acquire new information and skills specific to the task. This is consistent with earlier literature that has demonstrated the effectiveness of an error reducing paradigm to acquire and recall new verbal (Hillary et al., 2003), or more factual information (Goverover, Arango-Lasprilla, Hillary, Chiaravalloti, & DeLuca, 2009) in TBI patients with memory impairment.

The relevance of an error-reducing learning approach is confirmed by EG's rapid progress in acquiring the correct use of the mixer. Despite the difficulties reencountered by EG while transferring to his real-life context (third session), and at the beginning of the preparation of the soup (adaptation phase), EG learned to use this device effectively and his performances, at the end of the intervention, definitively improved. Evidence to date recommends an errorless learning (ELL) method for teaching taskspecific skills to TBI patients with severe memory impairment (Clare & Robert, 2008), yet very few studies have tested its effectiveness in the acquisition of functional and practical skills, essential for independent living. In a study focused on braininjured patients with severe memory deficits, Evans et al. (2000) found significant benefit when using ELL in learning face-name associations, but not for tasks involving analogue route-learning, or introducing information in an electronic memory aid. Our results suggest that it is possible to teach globally and severely impaired patients new few simple information essentially practical but still relevant for daily life (such as using a cooking device).

Some progress has also been observed, regarding the improvement in checking and self-monitoring processes. EG quickly acquired the proposed strategies, by successfully applying them during pencil -and-paper exercises. The decrease in the number of errors and commentaries during the sessions reflects improved self-monitoring capacities, as well as more structured work and a more systematic checking procedure. However, some hesitation and errors persisted, due to his impulsivity and to his inaccurate reading of the instructions. EG's difficulty in interiorizing the first step of the procedure ("stop and define the objective"), which was systematically omitted, should also be underlined. It seems, therefore, that, if EG was helped by the external instructions, the internalization of the global procedure and, in particular, its abstract and metacognitive dimensions, remained problematic. The GMT modified procedure was thus finally reduced to the sole use of the external support, with the description of the different stages of the task and the subsequential checking operations.

# **Difficulties of generalization**

The most important problems were encountered at the beginning of the second phase of the intervention, when EG had to apply the learned strategies and the previous acquisitions on his own, to the actual preparation of the soup. We then face a central problem in the rehabilitation of patients with severe cognitive impairments (especially in the executive functions): their inability of spontaneous generalization. In standard practice, therapists are often limited in their intervention as they can only work in the closed laboratory context. Our results underline the crucial importance of working in the patients' real context. Operating on single components or processes, in a decontextualized way, may not be sufficient when the aim is to help people regain autonomy in a specific daily task. On the contrary, direct and actual implementation on the task is mandatory and required.

# **Behavioural problems**

EG's behavioural problems represented a significant interference during the whole intervention. When defining the rehabilitation objectives, his reference caregiver in the sheltered home actually

reported some manifestations of verbal aggressiveness, yet, in her opinion, they were sporadic and easy to manage. EG had actually expressed his interest in our proposal, appreciating the idea of becoming the new "chef de la maison". However, difficulties soon appeared when we actually started to work. EG easily got nervous at having to repeat the same thing several times over and when he was confronted with his own difficulties. This resulted in the occurrence of errors and frequent interruptions of the task, making the standard learning procedures very laborious. The open environment of the workshops (near the supermarket) also contributed to frequent requests for alcohol and cigarettes, limiting EG's investment in the task. However, the main difficulties were encountered at the sheltered home, where, besides our preventive precautions, it was hard to maintain EG's motivation and to encourage him to pursue the task right to the end. The token economy techniques were little effective because even if EG was happy at the idea of getting a reward, this was not sufficient to avoid his impulsive outbursts. The phase that focused the checking processes was the only one without problems, maybe due to the more closed laboratory context.

The measures taken during our intervention (positive reinforcement measures, regular interviews with caregivers) allowed some acquisitions. However, as it is often the case, EG's impulsivity and disinhibiting problems, gradually increased, so limiting his investment in both our intervention and any other daily activity. Our clinical observations were in fact corroborated by his caregivers, who reported a significant increase in the frequency and intensity of EG's anger outbursts.

Overall, these observations lead to an interesting discussion concerning the possibilities of intervention in patients with behavioural disorders. What is obvious is certainly that the signs of behavioural alteration must be identified as early as possible, in order to intervene quickly. Our results suggest that, if we can limit the interference in these problems, some learning and acquisition is possible.

#### Self-awareness

Interestingly, when EG's inappropriate behaviours were discussed with him, he provided his own explanation, describing a feeling of frustration for the loss of autonomy, and intolerance toward the instructions imposed on him. It is, therefore, possible that EG's behavioural degradation and reject of any activity observed at the end of the intervention was linked to an improvement of his poor self-awareness (confirmed by the PCRS results), leading to a feeling of dissatisfaction and a desire for independence. Previous studies have investigated the effectiveness of self-awareness training during real-life occupational activities, to alleviate difficulties related to selfawareness and self-regulation, and to address functional outcomes in subjects with acquired brain damage (Fleming et al., 2006; Goverover, Johnston, Toglia, & DeLuca, 2007; Ownsworth et al., 2006). Results globally showed increased self-awareness during task execution as well as functional performances (decrease in error frequency). However, the effects seemed limited to self-awareness and selfmonitoring processes during task execution (on-line awareness), and did not extend to a gain in more global awareness of the subject's owns deficits (global self-awareness) (Goverover et al., 2007; Ownsworth et al., 2006). This does not seem to be the case in our patient. The difference in PCRS scores prior to commencing the program, and a post-intervention decrease, indicate that EG made gains in awareness over the intervention period, not only in the cooking activity. These findings replicate those of a previous study by Fleming et al. (2006) which include the same questionnaire to test the impact of an occupationbased intervention on the level of self-awareness in four patients with acquired brain injury (ABI).

It is also important to underline that EG gains in self-awareness were not maintained long-term. In fact, during a neuropsychological examination carried out four months after the end of the rehabilitation, only a few cognitive and behavioural complaints were reported for EG. It is, therefore, possible that the increased awareness after the intervention was caused more by working on an actual task and by the ongoing discussion with the therapist, than by real and stable internalization of his own difficulties and limits.

# Limitations of the study

number of limitations need to be Α acknowledged. As regards to the methodological plan, a first and main point to be considered concerns the method of analysis of the results. This project was merely clinical. For this reason, no statistical analyses were provided, but a qualitative assessment was prioritized. For the same clinical reason, the rehabilitation program was carried out by the same therapist who knew the patient and conducted the evaluation. Nevertheless, in order to reduce the element of subjectivity, the kitchen activity was analysed by two judges, one of them being blind to the therapeutic objectives. To show that the effects were specifically linked to the intervention, the evaluation should have included a control activity consisting of another task or recipe of the same difficulty as the soup preparation, but not object of intervention. However, this was beyond our clinical objective, which was related to improving EG's performance in preparing the soup,

without foreseeing some generalization to other tasks or recipes. A neuropsychological examination four months after the intervention showed, however, global stability in EG's cognitive difficulties, so excluding the possible effect of spontaneous recovery processes.

A second significant limitation concerns the various obstacles which we encountered in designing and carrying out the intervention. We do not dwell on the impact of behavioural disorders here, except to emphasize their influence on the number of sessions devoted to the actual work on the soup, and on the final goal of the intervention. We have in fact chosen to restrict the second phase of intervention to 10 sessions only, even though a longer training would have led to greater proceduralization of the task and greater benefits. We should also like to underline that the increase of EG's behavioural disturbances was the main reason why we chose to abandon the last objective of the intervention. In fact, considering EG's behavioural problems and his decreasing motivation for any daily activity (including cooking task), our last objective, to assign responsibility for soup preparation in the sheltered house, did not appear pertinent any longer. EG continued to contribute to the task though when he was in the mood. Ideally, a task previously invested by the patient would have been preferable.

Finally, we cannot exclude the fact that the interventions took place in different locations (neuropsychological office, workshop, sheltered house) might have been a confounding factor, with a negative impact on EG's performances. We have already pointed out that the main difficulties were encountered during the sessions at the sheltered house. A more accurate control for distractors in the environment would probably have been useful to limit the impact of this confounding factor on EG's performances.

## **Conclusions and future perspectives**

In conclusion, the present qualitative study provides some initial interesting perspectives in the rehabilitation of severe brain-injured patients, who are often neglected by the specific literature. Our results suggest that the abilities of severely impaired patients can be increased, in specific instrumental activities of daily life, by means of an individualized, multidimensional and intensive rehabilitation. However, a specific direct training phase on the task appears essential to offset the difficulties of spontaneous generalization. Specific difficulties in working with this clinical population have been underlined, with special regard to the importance of considering premorbid and motivational factors, as well as behavioural disturbances. We think that, in general, greater efforts should be made to provide clinicians with more precise and scientifically based indications to help severely damaged patients gain autonomy in daily activities. To this end, welldesigned single studies are particularly valuable (Manolov, Gast, Perdices, & Evans, 2014; Skolasky, 2016) and need to be further developed in this clinical population. Future studies should include a variety of assessment tools in order to understand the different and multiple processes implicated in an individuals' specific difficulties in real life. Intervention programs should be multi componential, including complementary strategies targeting these specific processes (e.g., Rochat, Manolov, Aboulafia -Brakha, Berner-Burkard, & Van der Linden, 2019) and promoting the client's engagement in the whole rehabilitation process (Brett, Sykes, & Pires-Yfantouda, 2017). Considering the urgent need for higher methodological quality studies, it would be particularly useful to complement the visual analysis with statistical procedures that are adapted for single case study designs (Manolov et al., 2014).

Finally, further research is needed to verify the consolidation of acquisitions and the long-term stability of the effects induced by the intervention on self-awareness deficits.

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