RESEARCH ARTICLE

Retrospective Study on the Pathway and the Outcome of Children Victims of Acquired Brain Injury Accompanied By a Mobile Unit of School Reintegration

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None of the authors have any conflict of interest.

Abstract:
Objectives: to retrace the care pathways and the academic pathways of brain-damaged children supported a Mobile Unit of School Reintegration (MUSR) and to identify factors associated with their long-term outcome.
Patients and methods: Retrospective study from the medical files of 53 children followed by the MUSR, conducted between November 2018 and April 2019.
Results: The cerebro-lesions were mainly caused by a craniocerebral trauma (83% of cases), with an average age of onset of 9.8 years. The duration of the initial hospitalization was 39 days on average. The mean length of follow-up was 37 months.
Long-term medical outcome was marked by 18.5% of medical complications, 29.6% of behavioral disorders and 9.2% of judiciary complications. The factors associated with long-term behavioral disorders were the age of onset ($p = 0.015$), the initial Glasgow score ($p = 0.025$), a head trauma related to a traffic accident ($p = 0.046$), a poor therapeutic alliance with the parents ($p < 0.001$), the absence of psychological follow-up ($p = 0.040$) and the existence of legal complications ($p = 0.001$). The factor associated with long-term legal complications was a poor therapeutic alliance with the parents ($p = 0.017$).
All the children followed were reintegrated into school, after an average of 6.4 months. A school reorientation was necessary in 49.9% of cases, associated with initial complications ($p = 0.035$), the existence of secondary brain aggressions of systemic origin ($p < 0.001$), the existence of antecedents ($p = 0.040$), and the autonomy level ($p = 0.023$).
Conclusion: The MUSR offers multidisciplinary, integrative and mobile cares, based on coordination of the care pathway and the academic pathway of children victims of acquired brain injuries.

Keywords: acquired brain injury, children, outcome, care pathway, behavior disorders, school reintegration, academic difficulties

Introduction:

Acquired brain injuries are the leading cause of death and acquired disability in children. They include head injuries, strokes, brain tumors, and meningoencephalitis. Their incidence, all causes combined, is estimated at 320 / 100,000 children / year [1-3]. The long-term repercussions of brain lesions acquired in childhood are very heavy on cognitive profile, functional autonomy, school curriculum, professional integration and quality of life [5-14].

In France, inclusive schooling is now a right for all children with disabilities. Historically, France had structured the global support of disabled children in a specific care and education sector known as the medico-social sector, and made up of specialized establishments depending on the nature of the disability. This system has encountered several limits: inequalities in access to care, a lack of diversity in school curricula, poor consideration of multiple disabilities, a lack of supply for acquired disabilities, etc.

Following the declaration of Salamanca in 1994 on the initiative of UNESCO, France promulgated on 02/11/2005, a law for equal opportunities, participation and citizenship of people with disabilities. This text was the first step in the evolution of French society towards an inclusive model, based on the principle of universal accessibility, in particular for common law care and education, as close as possible to the living environment of disabled people, for the benefit of society as a whole.

Then the law of 09/07/2013 of orientation and programming for the refoundation of the school of the republic reinforced the concept of inclusive education.

Since 1978, the Rehabilitation Expert Center of Brain Injuries in Limousin has structured a global support from the coma phase, through the rehabilitation phase, to the social and professional reintegration phase. The care pathways are personalized and coordinated between the hospital and the patients' living environments by mobile teams. The pediatric care offer is more recent: a Mobile Unit of School Reintegration was created in 2015, in order to improve the care pathway and the school reintegration of children victims of acquired brain injuries.

Objectives of the study:

The objectives of this retrospective study were to retrace the care pathways and the academic pathways of brain-damaged children supported by the Mobile Unit of School Reintegration and to identify factors associated with their long-term outcome.

Description of the Mobile School Reintegration Unit:

The Mobile Unit of School Reintegration Unit (MUSR) is composed of a Physical Medicine and Rehabilitation doctor, a neuropsychologist and a social worker. The objectives of the MUSR are to offer an early identification of specific disorders related to the cerebro-lesion, to adapt learning strategies, and to set up means of compensation in order to access to education in the best conditions.

The activity of the Mobile Unit of School Reintegration is divided in half in direct interventions with the child and his family, and in half in interventions intended for professionals who accompany him. The neuropsychologist travels through the child's living environment, his home, school or his medico-social establishment if necessary. With the child, the mission consists in setting up optimal compensations with regard to his cognitive capacities and his functioning in class. With professionals, the MUSR brings awareness, a theoretical framework and practical information which are used to understand learning difficulties and behavioral disorders. In addition, the MUSR ensures regular exchanges with the network of partners and continuous case-management for each accompanied child.

Patients and methods:

This is a retrospective study from the medical files of 53 children followed by the MUSR, conducted between November 2018 and April 2019. The research methodology MR004 was applied. Patients and their legal representatives were informed by post of the completion of the study and their right to object to the processing of their data. Out of the active file of 54 children, only one opposition was received by the data protection officer. The data collected focused on the circumstances and severity of the injuries, the child's environment and the quality of the therapeutic alliance with his parents, cognitive-behavioral impairment and the existence of associated disorders, the care pathway, school curriculum, and quality of professional integration.

- The criteria used to assess the circumstances and the initial seriousness were:
- the type of acquired brain injury (ABI), namely head trauma, brain tumor or other, the date and age of onset,
- the existence of antecedents and their nature, the initial Glasgow score, the presence of intracranial hypertension, the occurrence of secondary brain aggressions of systemic origin, the electroencephalographic anomalies found, the scores on the arousal scales carried out , the duration of post-traumatic amnesia, the occurrence of general medical complications.

The social context was approached by the family situation (classic family unit, separated parents, pre-existing social difficulties).

The quality of the therapeutic alliance was defined according to the presence of the child and at least one parent at medical consultations and to the follow-up by the parents of the advices and prescriptions issued. The therapeutic alliance was considered as good if appointments were honored and recommendations followed, average if certain appointments were missed but recommendations followed, and poor if appointments were missed and recommendations not followed.

The initial clinical presentation was detailed by the cognitive disorders presented, motor disorders and associated disorders.

The duration of hospital stay and any outpatient care relays were noted. The start of management by the MUSR was specified by its date and the motive of admission (prevention, academic difficulties, and behavioral disorders).

The evaluation of the evolution was based on the level of autonomy achieved and on the necessity or not of the pursuit of rehabilitations in liberal.

The resumption of schooling was assessed on the date of resumption and the conditions for resumption (accommodation or not). The evolution of schooling has been specified by the chosen orientations (common law or adapted) and the diplomas obtained. Long-term follow-up focused on follow-up procedures within the Expert Center (loss of view, cessation of follow-up, relay by the Mobile Unit of Professional Reintegration), the occurrence of long-term medical complications, the quality of social integration obtained (profession, independent housing, family status), and the possible occurrence of legal complications.

Most of the missing data were supplemented by telephone interviews with patients or their parents.

The comparison of the qualitative variables was carried out by a Xi2 test. The comparison of the quantitative data between

groups used the non-parametric Mann Whitney test.

Results:

53 children and young adults were included in the study. The causes of cerebro-lesion were mainly TC (83% of cases). The etiology of acquired cerebro-lesions is shown in Table 1.

The average age of onset of brain injury was 9.8 years. For TC, the Glasgow score was 10 on average, and the duration of post-traumatic amnesia was 8.7 days. The care pathway was characterized by a conventional hospitalization of 39 days on average and a relay of rehabilitation in liberal in 58.5% of cases. The average delay between the ABI and the admission in the Mobile Unit of School Reintegration was 3 years. Long-term follow-up was carried out in the majority of cases (2 lost of view). The mean length of follow-up was 37 months.

Long-term medical outcome is marked by 18.5% of medical complications, and 29.6% of behavioral disorders. On the medico-legal level, it was noted the occurrence of judiciary complications in 9.2% of cases.

Table 1: The etiology of acquired cerebro-lesions

Etiology of acquired brain injuries	Percentage of the population studied
Brain injury Of which road accidents	83% 50%
Stroke	5.7%
Encephalitis	3.8%
Tumor	1.9%
Other	5.7%

The factors associated with long-term behavioral disorders were the age of onset (7.5 ± 3.7 years with disorders *versus* 11.1 ± 5.7 years without disorders) ($p = 0.015$), the initial Glasgow score (8.3 ± 2.4 with disorders versus 11.1 ± 3.6 without disorders) ($p = 0.025$), a head trauma related to a traffic accident ($p = 0.046$), a poor therapeutic alliance with the parents ($p < 0.001$), the absence of psychological follow-up ($p = 0.040$) and the existence of legal complications ($p = 0.001$).

The factor associated with long-term legal complications was a poor therapeutic alliance with the parents ($p = 0.017$).

The school career was marked by an average return to schooling period of 6.4 months. The reasons for admission to the Mobile Unit of School Reintegration were academic difficulties in 64.8% of cases, support in preventing the occurrence of disorders in 25.9%, the existence of behavioral disorders in 11% and an orientation problem in 3% of cases.

All the children followed were reintegrated into school. But a school reorientation was necessary in 49.9% of cases, in ordinary establishments in 24% of cases and in adapted establishments in 25.9% of cases. From a distance, out of our still mostly minor population, the graduation rate is 39.6%, the average level of diplomas obtained is 4.5 (between a BAC level and a BAC +2 level).

The study found parameters associated with the academic pathway. The number of cognitive functions affected was associated with academic difficulties (p = 0.007). The need for reorientation was associated with initial complications (p = 0.035), the existence of secondary brain aggressions of systemic origin (p <0.001), the existence of antecedents (p = 0.040), and the autonomy level (p = 0.023).

Discussion:

1/ Long-term complications

Our study found the occurrence of long-term behavioral disorders in 29.6% of cases. This is consistent with the data in the literature, in particular the meta-analysis of Li and Liu from 2012 [13] which found the appearance of behavioral and / or psychiatric disorders in 10 to 50% of brain-damaged children, immediate or very delayed, linked not only to cognitive disorders, but also to the increase in environmental expectations. Grattan and Eslinger [14] had also shown the appearance or the increase in behavioral, social and emotional disorders in adolescence.

Behavioral disorders with medico-legal consequences were explained in the recommendations of good practice of the High Authority of Health (HAS) and French Society of Physical Medicine and Rehabilitation (SOFMER) of July 2013 [15] on the management of behavioral disorders of head injuries: it has been noted that a history of TC in childhood or adolescence increases the risk of psychiatric disorders (odds ratio 2.1) and, in men, it is significantly associated with subsequent psychiatric disorders with crime (odds ratio = 4.1).

2/ Factors associated with long-term behavioral disorders

Our study identifies factors associated with long-term behavioral disorders: the age of onset (p = 0.015), the initial Glasgow score (p = 0.025), a head trauma caused by a traffic accident (p = 0.046), a poor therapeutic alliance with parents (p <0.001), a lack of psychological follow-up (p = 0.040), legal complications (p = 0.001).

In the literature, there are factors associated with similar cognitive and functional outcomes. The pejorative role of the severity of the initial trauma has been described several times [16-18]. Ryan, in 2016 [19], showed that the most pejorative long-term social outcomes were associated with family dysfunction and a lack of psychological care. Chavez-Arana [20] found that the stressors of the immediate environment (parental stress, dysfunctional parenting, executive dysfunction, anxiety traits and depressive symptoms in parents) were predictive in brain-damaged children of a negative cognitive profile and mental health troubles from a distance.

3/ Specificities of the academic pathway

Our study confirms the existence of a major impact of the acquired brain injury on learning and schooling, with a need for reorientation in half of the cases.

A similar development was described by Ewing-Cobbs [16], who found redoubling and / or the need for reorientation in almost half of the cases in a group of children victims of head trauma before 6 years, in comparison of a control group. The rate of academic difficulties was 18 times higher than the control group.

Kingery [21] has shown the need for long-term adaptations to school, almost 7 years after the trauma, and the difficulty of effectively meeting these needs.

In addition, our study finds the impact of acquired brain damage on integration into adulthood. This was described by Anderson in 2009 [7], who identified for children with a history of mild to severe TC, a baccalaureate graduation rate 3 times lower, a university graduation rate 2 , 3 times lower, an unemployment rate 1.7 times higher, and a

rate of access to skilled jobs 2.1 times lower compared to the general population.

4/ Factors associated with the need for scholar reorientation

In our study, the need for scholar reorientation is associated with initial complications (p = 0.035), the occurrence of secondary systemic brain attacks (p <0.001), the existence of antecedents (p = 0.040) and the autonomy level (p = 0.023). Ewing-Cobbs [16] had previously shown that the intelligence quotient and long-term school performance in children victims head trauma in early childhood were correlated with the initial Glasgow score and the number of intracranial lesions. In 2019, Keenan [22] (USA) analyzed the health and educational needs of children in the first year after their head injury. He concluded that, at 3 months of the trauma, a low social capital, a low income, a history of psychological disorder are associated with greater health needs, and that the severity of the head trauma is predictive of educational needs. At 12 months of the trauma, health needs were also correlated with the implementation of early rehabilitation, and family functioning impacted both health and school needs.

5/ Support modalities

Our study confirms that the acquired brain injury marks a disruption in the child's life course. Indeed, the child is separated from his usual environment for a long period: the average hospital stay is 39 days, and the average time to return to school is more than 6 months.

In this first retrospective study, there was a long delay, 3 years, for admission in the Mobile Unit of School Reintegration. Two hypotheses can explain this long delay: the response to needs previously not covered at the time of the creation of the Unit in 2015, and the appearance of cognitive-behavioral disorders at a distance because of the cerebral maturation and the increase in requirements of the school environment.

Some authors have highlighted the impact of the delay in specialized assessment [19], and access to specialized rehabilitative care [18].

In France, early reintegration support is recommended [15].

Our study also shows that the lack of care in psychology and psychiatry negatively impacts the occurrence of long-term behavioral disorders. In our experience, these results are linked to the poor therapeutic alliance and refusals by parents of these specialized follow-ups. The poor therapeutic alliance with the parents, defined if they missed appointments and did not follow medical recommendations, is very significantly associated both with the existence of behavioral problems at a distance (p <0.001) and the occurrence of judiciary complications (p = 0.017). The implementation of specific actions towards the most deprived families seems essential to prevent the loss of chance of the children concerned. A very recent review of the literature [23] concluded that there is a high level of evidence of targeted interventions on families in the cognitive and emotional rehabilitation of children with acquired brain damage.

Moreover, our study finds that a lower level of autonomy penalizes the academic outcome. Therefore, global support must also focus on the specific management of associated disorders, in particular neurosensory troubles.

Finally, the existence of long-term complications, confirmed by our results, implies the need for long-term follow-up, also recommended by the HAS [15].

In addition, our study allows us to make suggestions to improve the scholar pathway and inclusion of brain-damaged children. Thanks to a joint coordination of the care pathway and the academic pathway

including direct interventions at school, 100% of the children supported by our MUSR have successful school integration. In France, the current obstacles to inclusive education were identified by the United Nations special reporter on the rights of people with disabilities in the January 2019 report [24], as well as by the rights defender in her April opinion. 2019 [25]. The Inclusive School Plan, in force since July 2018, aims to simplify the educational pathways of children with disabilities, develop resources specific to disability in scholar establishments, improve the training of educative professionals, coordinate various supports, and strengthen links with health professionals. In this sense, the Esquirol Hospital Center, the Limoges Academy and the Regional Health Agency of Nouvelle Aquitaine signed a partnership agreement in September 2019.

Perspectives:

In order to improve the therapeutic alliance with all families, the Expert Center of Rehabilitation is currently developing 3 new support methods to improve the therapeutic alliance: a therapeutic education program dedicated to brain-damaged children and their parents; family systemic psychotherapy; and a strengthened partnership with social services. Finally, in order to benefit as many people as possible and to disseminate expertise outside the hospital, the Center Expert wishes to experiment with a system for coordinating liberal rehabilitation pathways open to children with complex neurological disabilities and based on telemedicine.

Conclusion:

The Cerebrolesion Expert Center of the Esquirol Hospital Center offers multidisciplinary, integrative and mobile cares, based on coordination of both the care pathway and the academic pathway of children victims of acquired brain injuries. The care pathway could be optimized by early assessment, stronger involvement of families, particularly in relation to psychic care, and better care for associated disorders, in particular neuro-visual troubles. The academic pathway is facilitated by the awareness of the teaching teams, concrete recommendations, regular exchanges and long-term follow-up.

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