

# Activities and participation after mild traumatic brain injury

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## Relevance

A traumatic brain injury (TBI) is a form of acquired brain injury, and refers to sudden damage to the brain resulting from external mechanical force, for example when the head hits an object due to accidents at home, school or in traffic, or when an object pierces the skull and enters brain tissue.<sup>1-2</sup> Each year, a number of approximately 13,000 children and adolescents aged between 0-24 years old suffer a traumatic brain injury (TBI) in The Netherlands, the majority (80%) of which are mild (MTBI).<sup>3-4</sup>

In our research we used the definition of MTBI according to the criteria established by the American Congress of Rehabilitation Medicine (ACRM) and the WHO Collaborating Centre for Neurotrauma Task Force on Mild Traumatic Brain Injury<sup>5</sup>: ‘a Glasgow Coma Scale (GSC) score of 13-15 and at least one of the following: (1) loss of consciousness of no more than 30 minutes, (2), Post Traumatic Amnesia (PTA) no longer than 24 hours, (3) any alteration in mental state at the time of the injury, (4) focal neurological deficit(s) that may or may not be transient’.

Most children with MTBI are expected to recover completely and do not receive any follow-up care after discharge from the emergency department.<sup>6</sup> However, when children return home after MTBI, between 6-43% of them suffer from a variety of symptoms.<sup>7-11</sup> These symptoms are often defined as post-concussive symptoms (PCS) and may be found in the physical (e.g. headache), cognitive (e.g. trouble concentrating), emotional (e.g. stress), and behavioural (e.g. irritability) domains, and can last up to six months post-injury or longer.<sup>7-11</sup> As a consequence of these symptoms, children after MTBI may experience trouble or limitations in the area of activities and participation such as in school, social relations and play<sup>12-14</sup>, (chapter 3).

Activities and participation are very important for the development of a child, because it helps children to develop different skills and competencies, develop physically and cognitively, develop their own identity and set different life goals.<sup>15</sup> Therefore, healthcare providers for children with MTBI should focus on early prevention of limitations in this area.

Since most children are expected to fully recover from MTBI, we have to look for ways to organize healthcare services especially for children with MTBI who may not recover completely by nature. Therefore, the first step we took was to predict which children may benefit from follow-up care after discharge from the emergency department (chapter 4). Preventive treatment care is preferred because the symptoms that children may experience after MTBI are often not recognized and therefore not treated adequately. The second step we took was the development and evaluation of an early psychoeducational preventive intervention (the Brains Ahead! intervention) for children with MTBI and their caregivers.<sup>16</sup>

The results of the studies into the feasibility and effect of this intervention were positive (chapters 7 and 8). Therefore, we believe that the Brains Ahead! intervention is valuable for society and recommend it for use in clinical practice. In order to fit the intervention to the Dutch healthcare organization, we suggest a stepped-care approach for children after MTBI (chapter 9).

### **Target groups**

The findings of our research are of relevance for children with MTBI, their parents or caregivers, healthcare professionals, and health policy-makers.

Children with MTBI will profit from our research as it emphasizes that not all children recover completely from MTBI by nature. The need for information at discharge from the emergency room/hospital in general has become clearer, especially for those children who are at risk for long-term problems based on the predictors for outcome after MTBI. The first steps into the construction of a prediction model have been taken, and the importance of personal and psychosocial factors is emphasized (chapter 4). For children who are at risk for long-term problems after MTBI, we developed an early psychoeducational intervention,<sup>16</sup> with promising feasibility and effect results (chapters 7 and 8). The intervention is partly standardized and partly individualized, and as a consequence, the healthcare process can be better tailored to the individual needs of children who are at risk for long term problems after MTBI.

Parents or caregivers of children with MTBI are expected to profit from our research as it points out that indeed, many children seem to recover completely by nature, which may be reassuring. The research also highlights the importance of taking the perspective of the caregiver along in the recovery process, since it may differ from that of the child itself. Furthermore, it emphasized the need to involve the family in the follow-up care process, and provide them with reassurance, information on symptoms that can be expected after the injury, and individualized advice on how to let their child return to activities and participation, which elements are all embedded in the Brains Ahead! intervention.<sup>16</sup> Parents or caregivers may feel strengthened by the obtained knowledge on MTBI in children and more ensured about what is wise when stimulating their child to return to activities and participation.

Healthcare professionals working in the field of children with MTBI (e.g. neurologists, general practitioners, psychologists, occupational therapists, and rehabilitation specialists) will profit from our findings as well. Our study provides knowledge on predictors of outcome which helps them to decide which children need to be followed up in order to prevent long term problems from occurring. Secondly, our study provides a psychoeducational intervention, with standardized elements that

can easily be implemented in healthcare.<sup>16</sup> Although the intervention's primary purpose is prevention of long-term problems after childhood MTBI, the standardized information may also be used to provide patients and their caregivers with psychoeducation in child rehabilitation care.

Finally, our results are of importance for health policy-makers. In the past few years, much has been studied about the recovery of children from MTBI. Our study emphasizes that, since most, but not all children recover naturally from MTBI, follow-up care for these children should be organized. Taking the organizational matters of several clinical settings (e.g. emergency departments, general practitioners) into account, we provide the health policy-makers with a stepped-care approach for children after MTBI that fits the Dutch healthcare organization, may improve care efficiency and help to achieve higher health-related gains (chapter 9).

### **Activities and products**

Our results help to detect those children who are at risk of long-term problems after MTBI based on predictive factors. The importance of personal and psychosocial factors for the prediction of outcome after childhood MTBI is emphasized, and should be further investigated to complete the prediction model.

For the children who are at risk of long-term problems, we developed the Brains Ahead! intervention. The intervention consists of a standardized and individualized psychoeducational session with written take-home information, and follow-up telephone call(s). Reassurance, information about causes, possible consequences, and advice about returning to activities and participation are main elements of the intervention. The elements are described in more detail in the treatment protocol of the Brains Ahead! intervention for children and adolescents with mild traumatic brain injury and their caregivers in chapter 6.<sup>16</sup>

The results of our research show that children who are at risk for long-term problems after MTBI may benefit from the Brains Ahead! intervention. The findings also show that the Brains Ahead! intervention in its current form needs some adjustments in order to better match with clinical practice possibilities and the wishes from the children and their caregivers.

Altogether, these findings both challenged and supported us to create the proposal of a stepped-care approach for children after MTBI (chapter 9). During the study, we learned that most children and caregivers were relieved when the child was discharged from the emergency department and hurried home, with the questions on the recovery process, occurring symptoms, and the need for individualized advice on returning to activities and participation emerging in the following days. Since time and manpower is lacking at the emergency department, standardized information could be offered directly by primary care after referral from

the emergency department. More individualized information focused on the child's symptoms and advice on activities and participation fitting their personal situation, could be offered either at a scheduled appointment one or two weeks after the injury, or scheduled at the patient's request. Such a stratified management approach to target the provision of primary care may, in addition to improved care efficiency and higher health gains, provide substantial economic benefits compared with the current usual care.<sup>17</sup>

## **Innovation**

In our research we highlighted that a substantial number of children suffer from problems after MTBI, and experience restrictions in activities and participation. Up until now, the usual care for all children leaving the emergency department after MTBI consists of a concise information brochure, with recommendations to return to the general practitioner or hospital in case of frequent vomiting, increasing drowsiness, and/ or an increase in other complaints during the following days.<sup>18</sup>

Since most children recover completely from MTBI by nature, not all children need further follow-up care. Our research was innovative in providing knowledge on predictive factors for long-term problems on activities and participation after childhood MTBI, and was the first to examine multiple predictors from a biopsychosocial perspective following the relevant ICF-CY categories<sup>19</sup> in one comprehensive model, from both the perspective of the caregiver and the child (chapter 4). With this knowledge, a better early identification of children who are at risk of long-term limitations and might benefit from early interventions is possible.

The results of our scoping review into what is known about early interventions for children after MTBI, taught us that information and education about the injury and its consequences are recommended, ideally followed by a consultation in which individualized advice and reassurance is provided. The family should be involved, and clinical recommendations suggest a step-by-step return to activities and participation (chapter 5). Based on these findings, we developed the Brains Ahead! intervention for children with MTBI.<sup>16</sup>

The Brains Ahead! intervention was innovative in prospectively intending to prevent long-term problems related to activities and participation in children and adolescents aged 6 to 18 years old following MTBI. The intervention combines an inventory of symptoms, psychoeducation, and follow-up, and involves the child's family in the process.

Our intervention study was carried out highly in agreement with the Medical Research Council (MRC) framework for development, evaluation and implementation of complex interventions.<sup>20</sup> This framework suggests that for developing and evaluating complex interventions, the following steps should be



passed; (1) to identify existing evidence, (2) to identify and develop theory, with the rationale for the complex intervention and a theoretical understanding of the likely process of change by drawing on existing evidence, (3) to assess effectiveness with a randomized controlled study, (4) to decide which outcomes are most important, which are secondary, and how they will deal with multiple outcomes in the analysis, (5) to consider which sources of variation in outcomes matter and to plan appropriate subgroup analyses, and (6) to perform a process evaluation, in order to provide valuable insight into why an intervention fails or has unexpected consequences, or why a successful intervention works and how it can be optimised. They suggest a process evaluation nested inside a trial, which can be used to assess fidelity and equality of implementation, clarify causal mechanisms, and identify contextual factors associated with variation in outcome.

Although it might seem evident that development and evaluation of complex interventions should be constructed following such fundamental frameworks, the actual number of studies adopting all framework steps is limited. The study-and treatment protocol of Brains ahead! were published and may be used as a model for new researches wanting to follow this framework.

Finally, our research offers a stepped-care approach plan to innovate and optimize the healthcare for children with MTBI (chapter 9).

### **Schedule and implementation**

The Brains Ahead! intervention is feasible and effective for preventing long-term symptoms and problems on quality of life. Implementation of the intervention in clinical settings is therefore recommended. The process of the Brains Ahead! intervention, however, needs some adjustments on timing and distribution of the intervention-components in order to better match with clinical practice possibilities and the wishes from the children and their caregivers, and to fit the proposed stepped-care approach for children with MTBI. The minor adjustments in the Brains Ahead! intervention process that are needed for this purpose, are described in further detail in chapter 9 of this manuscript.

The proposed stratified management approach to target the provision of primary care may, in addition to improved care efficiency and higher health gains, provide substantial economic benefits compared with the current usual care. Funding is necessary to finance the adjustment-process of the intervention, and implementation in clinical settings as intended. Furthermore, health policy-makers should be involved in the process of integrating the stepped-care approach for children after MTBI in the Dutch healthcare organization. One can, for example, think of the funding and organization of the training that general practitioners or physician assistants may need in order to carry out the Brains Ahead! intervention,

and the proper distribution of the written standardized information. Possibly, opportunities may also be found in providing parts of the information by e-health. However, funding would be needed to convert the written information to e-health accessible information as well, and precautions for use by the general population without the guidance of trained professionals should be concerned.

Distribution of the knowledge that was collected with our research was performed in several ways. In order to share knowledge with other researchers, study- and treatment protocols were published in international journals. Furthermore, newsletters were published on a regular basis to inform healthcare professionals, participants and other interested parties about the study-progress and outcomes. The newsletters could be downloaded at the Brains Ahead! website: [www.brainsahead.nl](http://www.brainsahead.nl).

Furthermore, the design and outcomes of the two Brains Ahead! studies were presented at several national and international conferences. Examples of the national conferences are The Brain Awareness Week (2015 and 2018), Hersenletselcongres (2016, 2017, and 2018), and Samen Nog Beter congress (2017). Examples of the international conferences are the International Conference on Pediatric Acquired Brain Injury (IPBIS Rome 2017, and Belfast 2018), International Brain Injury Association (IBIA 2016), and the Conference in Neuropsychological Rehabilitation of the Special Interest Group of the WFNR (Granada 2019). Also, presentations about the designs and outcomes of the Brains Ahead! studies were given to the participating hospitals in the studies, and several other interested parties such as rehabilitation centers, psychiatry/psychology departments of hospitals, and national workgroups for children with acquired brain injury. Finally, an invited symposium “What’s new, what’s next? Kinderen met traumatisch hersenletsel” was organized, during which the final results of the Brains Ahead! studies were shared.



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