



**Universiteit  
Leiden**  
The Netherlands

## **On the road to optimize rehabilitation for young individuals with acquired brain injury**

Allonsius, F.

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# **CHAPTER 1**

General introduction

## **Definitions, incidence, classification of severity, and stages of recovery of Acquired Brain Injury among young individuals between 4 and 25 years old**

### **Definitions**

Acquired Brain Injury (ABI) is a collective term for brain injury that occurs after birth and leads to a disruption in the developmental (life) line.<sup>1</sup> ABI encompasses both traumatic brain injury (TBI) and non-traumatic brain injury (nTBI). TBI is caused by external trauma, such as traffic and sports accidents, or violence, while nTBI refers to brain injuries caused by internal factors like brain tumors, stroke, or meningitis.<sup>1</sup>

### **Incidence**

ABI has a substantial global incidence, with an estimated 54-60 million cases of TBI and 15 million cases of nTBI occurring annually.<sup>2</sup> The global incidence rate of TBI in children and adolescents aged 0 to 18 years is estimated to range from 47 to 280 per 100,000 individuals per year, but the rates vary across countries.<sup>3</sup> No global annual incidence rates for nTBI are available, likely due to the diverse range of causes and different registration systems. For stroke specifically a systematic review and meta-analysis on pediatric stroke in hospitals found an estimated global pooled incidence rate for all ischemic strokes in children up to 18 years old of 5.6 per 100,000.<sup>4</sup> Regarding ABI in general, studies conducted in the United States and Finland have shown an increasing incidence and prevalence of ABI among young individuals over the past years.<sup>3,5,6</sup>

In the Netherlands in 2013 the estimated yearly incidence of ABI among young individuals under the age of 25 was 586 per 100,000 citizens for TBI and 191 for nTBI.<sup>7</sup> Consistent with international literature,<sup>3,5,6</sup> a Dutch monitor on national child safety indicated a rise in the incidence of TBI cases due to increasing traffic incidents.<sup>8</sup>

### **Classification of severity and stages of recovery**

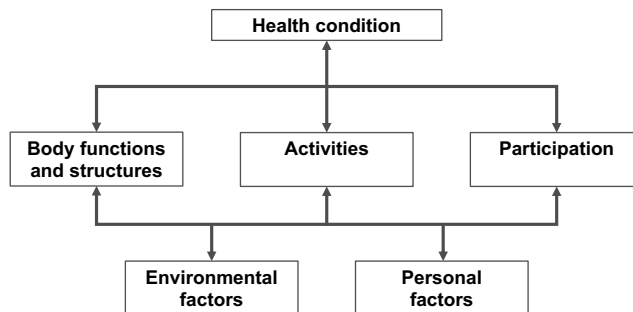
The severity of TBI is typically determined by means of the Glasgow Coma Scale<sup>9</sup> and the duration of Post Traumatic Amnesia,<sup>10</sup> which are both generally determined at hospital admission. In case of nTBI, the modified Rankin Scale is often used in pediatric stroke.<sup>11</sup> However, there is currently no severity classification available for other specific nTBI subtypes, such as brain tumors. It is important to note that these severity classifications are only applicable to young individuals with TBI or nTBI who were admitted to or were assessed in the hospital so that they are not available for the whole ABI population.

With respect to recovery after TBI and some forms of nTBI such as stroke, three general stages can be identified.<sup>7,12,13</sup> The acute phase, the first hours to weeks after onset, during

which young individuals with ABI may be either hospitalized or not, depending on the cause, origin, and timing of the injury. The second stage is the subacute or recovery period, during which patients may be treated either at home, with or without primary care treatment like physical therapy, or in a hospital or rehabilitation center. Finally, for TBI and some forms of nTBI, the participation or chronic phase is when most individuals are returning to participation in society and in the community, such as in school, work, and sports. Treatment may still be necessary during this stage. The duration of these stages can vary widely among individuals due to potential relapses and differences regarding specific consequences.<sup>12-17</sup> Approximately 70% of young individuals with ABI recover within the first six months to one year following the injury, while the remaining 30% experiences persistent daily-life consequences.<sup>7,12-20</sup> Notably, the severity of the brain injury was found to only have a weak relation with the persistence of these consequences.<sup>7,18-21</sup>

### **Consequences of ABI in young individuals with ABI (4-25 years old).**

The consequences of ABI can be classified according to the World Health Organization (WHO) International Classification of Functioning, Disability, and Health (ICF). This classification system describes the consequences of a health condition across various domains: body functions and structures, activities and participation, and environmental and personal factors (Figure 1).<sup>22</sup> In research cohorts, the ICF offers the potential to be used as a framework to systematically select assessments and interventions for children, adolescents and young adults covering the age range of 4-25 years with a specific health condition.<sup>25,26</sup>



World Health Organization (WHO), 2012

**Figure 1.** The International Classification of Functioning, Disability, and Health (ICF) framework.

Apart from a description of the consequences of a health condition per domain, the overall health status of an individual including his/her/x physical, emotional, cognitive and social

functioning is commonly defined as Health-Related Quality of Life (HRQoL).<sup>22,27</sup> In children, adolescents, and young adults with ABI the consequences may persist and negatively affect the totality of physical, mental, cognitive, and social-emotional skills and competencies.<sup>7,19,21,28-30</sup> The negative effects of ABI on HRQoL have been demonstrated in pediatric TBI,<sup>28</sup> pediatric stroke, and brain tumor populations.<sup>29,30</sup> Diminished HRQoL may persist for years after the brain injury onset and may influence various transition moments from childhood to adulthood.<sup>25,26,31</sup>

### **Body functions and structures: Fatigue**

In terms of the ICF domain body functions and structures, the potential consequences of ABI involve physical problems such as motor impairments, and pain.<sup>32,33</sup> Moreover, one of the most frequently reported consequences of ABI is fatigue.<sup>7,18,19,34</sup> Fatigue is defined as ‘the experience of exhaustion and a decreased capacity for physical or mental activity because of an imbalance in the availability, use or restoration of resources needed to perform the activity’.<sup>35</sup> Fatigue after ABI was found to have a negative impact on physical, cognitive, and social functioning.<sup>34,36</sup> Young patients must adjust their lives to manage ABI-related fatigue, often resulting in reduced participation, for example by discontinued sports activities and limited school attendance. Fatigue is particularly prevalent during the transitions from childhood to adulthood.<sup>34</sup> Factors associated with being more tired include nTBI and older age i.e., adolescence or young adulthood.<sup>36</sup>

To date, the occurrence of fatigue and its multidirectional influence on participation restrictions have been explored among young patients with ABI, both cross-sectionally and longitudinally.<sup>36-39</sup> However, it is not known how severely fatigued young individuals (4-25 years old) with ABI referred to rehabilitation are, and there is a lack of knowledge regarding the persistence of fatigue over time after referral to rehabilitation and its longitudinal relationship with participation.

### **Activities and participation**

According to the ICF, activities refer to the performance of tasks or actions by young individuals.<sup>22</sup> Limitations in mobility (walking, cycling) and self-care are commonly reported consequences of ABI in young individuals.<sup>22,40-42</sup> The ICF defines participation as ‘involvement in a life situation’.<sup>22</sup> Participation can be operationalized using two key elements: attendance i.e., ‘being present’ and involvement i.e., ‘active engagement’.<sup>43</sup> The ability to participate in valued life situations at home, school, work, and in the community is crucial for healthy development during the transitions from childhood to adulthood.<sup>43</sup> ABI in children, adolescents, and young adults can lead to significant participation restrictions, which are substantially higher compared to their healthy peers.<sup>40,43</sup> Studies on participation restrictions

in (Dutch) children and adolescents with disabilities, including TBI, have identified many limitations in social and educational activities.<sup>40,44-46</sup> Factors associated with greater participation restrictions include impaired motor, cognitive, behavioral, and sensory functioning.<sup>40,45,46</sup> With the exploration of participation, it is important to realize that perspectives on participation between young individuals and their parents may differ.<sup>44</sup>

Similar to the consequences on the level of body functions and structures, most studies on the impact of ABI on activities and participation have not encompassed the entire population of young patients (4-25 years old) with ABI in a rehabilitation cohort. Additionally, potential differences in perspectives on participation between patients and their parents have often not been considered. Therefore, knowledge regarding participation restrictions in young individuals with ABI referred to rehabilitation remains an under-researched topic.

### **Environmental factors: Impact on the family**

The consequences of ABI among young individuals often have a significant impact on their families as well. This impact can be of emotional, social, or practical nature, e.g., consisting of increased stress, worries, or changes in family routines, roles, and responsibilities.<sup>18,45,47,48</sup>

Previous cross-sectional studies have emphasized the existence of family impact throughout all stages of recovery of young patients with both TBI and nTBI.<sup>48-53</sup> Its occurrence was found to be influenced by, among other aspects, the unexpected onset, the less visible consequences and the uncertain prognosis.<sup>54-57</sup> The full extent of the impact on the family often appears only in the phase of everyday life at home and community reintegration. Longitudinal studies among families of young individuals with TBI have found that significant family burden and stress, regardless of the cause or severity of the brain injury, may persist longer than 12 months after the onset of ABI.<sup>54-58</sup> However, these studies have mostly included patients with TBI,<sup>54-57</sup> or patients with more severe injuries,<sup>54,56,58</sup> or they have focused only on limited aspects of family functioning.<sup>54,56</sup>

Overall, research into the extent and course of the impact on the family and its determinants are scarce, in particular for the group of young individuals referred to rehabilitation after ABI.

### **Management of ABI in young individuals: the role of medical specialist rehabilitation**

Regardless of the stage of recovery, the ultimate goal of rehabilitation is to enable the patient to fully participate in society.<sup>22,59</sup> When daily-life consequences persist after ABI in a young person between 4 and 25 years old, general practitioners or medical specialists often assess if there is an indication for medical specialist rehabilitation treatment. In the

Netherlands, most of the 16 specialized medical rehabilitation facilities (Medical Specialist Rehabilitation Centers, further designated as rehabilitation centers) provide inpatient or outpatient treatment for patients with ABI. In most cases patients are referred to outpatient rehabilitation care. Rehabilitation care in the Netherlands is typically delivered by professionals working in multidisciplinary teams.<sup>12</sup> The care is, apart from the nature and severity of the consequences of the ABI, tailored to the life stage of the young person and the family, considering their wishes and needs.<sup>60</sup>

In most rehabilitation centers in the Netherlands, the Dutch Care Standard for TBI in children and youth (Zorgstandaard traumatisch hersenletsel kinderen & jongeren, 2016) is used.<sup>12</sup> This standard is generally considered to be applicable to young individuals with nTBI as well.<sup>12</sup> In this standard,<sup>12</sup> it is described that young individuals between 4 and 25 years old with persisting daily life consequences after ABI could benefit from primary care or medical specialist rehabilitation care. Knowledge regarding the nature and severity of persisting daily-life consequences after ABI in young patients and their families at the time of referral to outpatient rehabilitation in the Netherlands is however limited. Research is needed to address this knowledge gap and further optimize rehabilitation treatment for this group.

Medical specialist rehabilitation aligns with the principles of value-based healthcare (VBHC).<sup>61</sup> VBHC states that the value in healthcare is the measured improvement in patient health outcomes relative to the costs, in order to optimize the value of care for patients and their families. One of the VBHC principles underlines the importance of providing outcomes that matter to all patients, putting patients at the center of healthcare and care standards are an operationalization of that statement.<sup>61,62</sup> The organization of care within multidisciplinary care pathways and the delivery of care across facilities are fundamental components of VBHC as well.<sup>61,62</sup> Therefore, it is crucial to ensure that prioritization extends beyond optimal care within the rehabilitation center itself, encompassing the seamless alignment of the referral process and potential follow-up treatments in primary care.

Regarding the delivery of rehabilitative care for young persons with ABI, age-appropriate care and the specific needs during transition moments of an individual are considered important elements.<sup>25,26,31</sup> The duration of rehabilitation can vary greatly, depending on the type and severity of the brain injury, as well as other factors such as the individual's age, overall health, and personal rehabilitation goals.<sup>12,60</sup>

**A cohort of young patients and their families referred to outpatient rehabilitation: research project "Participate?!"**

To gain more insight into the daily-life consequences of ABI for young patients who are referred to medical specialist rehabilitation and their families, the "Participate?!" project (in

Dutch: “Meedoen?!”) was initiated. The project was approved by the Medical Ethical Committee of the Leiden University Medical Center (LUMC) (P15.165) and started in 2015 with funding from the Dutch Brain Foundation (Hersenstichting). The goals were to gain more insight into the consequences of ABI over the various domains of the ICF (body functions/structures, activities/participation, and environmental factors including HRQoL, fatigue, participation, and family impact) in a cohort of young patients with ABI between 4 and 25 years old and their families referred to an outpatient rehabilitation center in the Netherlands. This research project was conducted in collaboration with a Dutch national consortium, called “Brain Injury and Youth” (in Dutch: Hersenletsel en Jeugd, HeJ), which consisted of pediatric rehabilitation physicians.

The consortium initiated several projects to improve and monitor the current care and education for young patients with ABI and their parents, focusing on cognitive, physical, and emotional consequences.<sup>7,19,36,63</sup> In this project, a questionnaire was developed in consensus with the Brain Injury and Youth consortium. The questionnaire included parent and patient-reported outcome measures (PROMs) to assess HRQoL, fatigue, participation, and family impact.

The use of PROMs in (pediatric) rehabilitation practice is recommended to assess well-being and disability levels.<sup>12,64-66</sup> Additionally, the use of health outcomes data is promoted in line with VBHC principles to improve outcomes that are important to patients.<sup>62</sup> Similarly, outcome measurement for the patients’ families, such as family impact, is crucial for VBHC as well.<sup>62</sup>

### **The road towards a national rehabilitation framework for young individuals with ABI: The research project “Participate?! Next Step”**

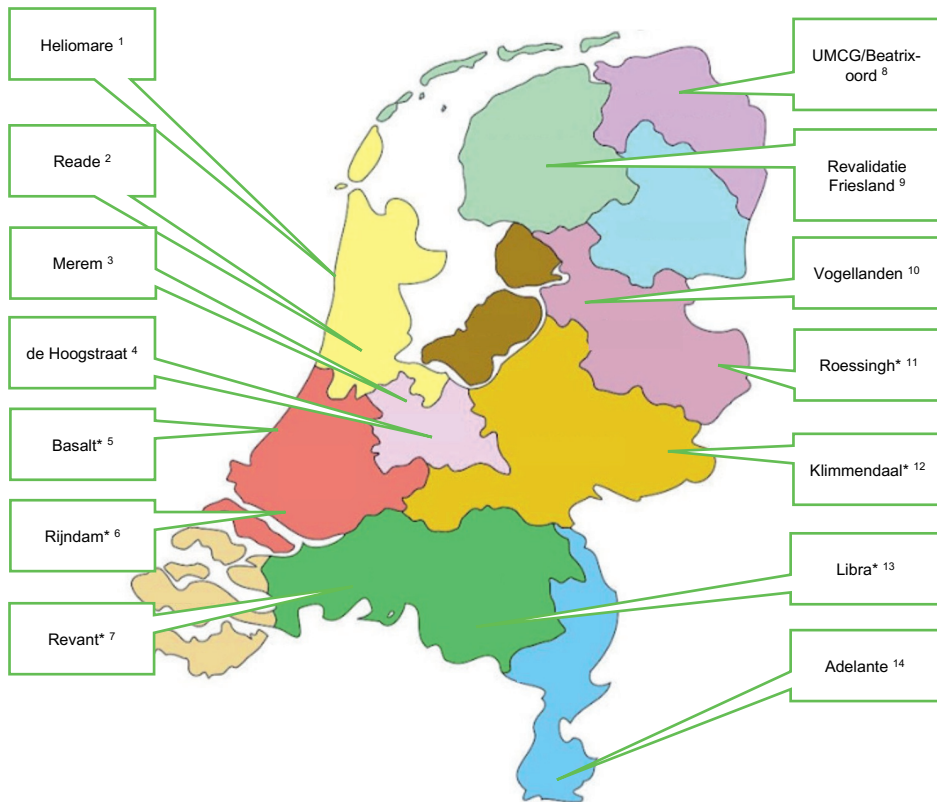
As a follow-up to a successful collaboration between rehabilitation centers in the “Participate?!” project, rehabilitation professionals, including rehabilitation physicians, psychologists, physical therapists, occupational therapists, speech therapists, and social workers, showed a growing interest to identify potential variations in practice among rehabilitation centers and harmonizing the delivery of care for the population. This interest aligned with the principles of VBHC where the development of care pathways is advocated and was recommended in the literature on pediatric rehabilitation care.<sup>12,25,62,66</sup>

To take the “next step”, the Participate?! project needed to continue, identifying differences, and strengthening collaborations among rehabilitation centers to further optimize care for young patients with ABI and their families. Consequently, in 2020, the “Participate?! Next Step” research project was initiated. This project was approved by the Medical Ethical



Committee of the LUMC (P15.165-addendum-1.0) and received funding from the Dutch Brain Foundation. A group of lead experts from participating rehabilitation centers was selected to support the project and strengthen collaboration. These lead experts represented their respective rehabilitation centers throughout the project and played a role in executing various parts of the project. Fourteen rehabilitation centers (Figure 2) committed to the project with the aim of strengthening collaborations and collectively optimizing the delivery of care for young individuals with ABI referred to medical specialist rehabilitation and their families.

The extent of potential variations among Dutch rehabilitation centers in the structure of care for young individuals with ABI, such as admission and discharge criteria, care organization, and aftercare, is currently unknown. Furthermore, as the commonly used standard of care does not specify exact structures and rehabilitation content,<sup>12</sup> it is expected that each rehabilitation center has its own approach to treating young individuals with ABI.



**Figure 2.** Participating rehabilitation centers that provide outpatient rehabilitation for young patients with ABI in the Netherlands.

Participating Rehabilitation Centers: <sup>1</sup> Heliomare, Wijk aan Zee; <sup>2</sup> Reade, Amsterdam; <sup>3</sup> Merem, Hilversum; <sup>4</sup> de Hoogstraat, Utrecht; <sup>5</sup> Basalt, The Hague; <sup>6</sup> Rijndam, Rotterdam; <sup>7</sup> Revant, Breda; <sup>8</sup> UMCG/Beatrixoord, Groningen; <sup>9</sup> Revalidatie Friesland, Beetsterzwaag; <sup>10</sup> Vogellanden, Zwolle; <sup>11</sup> Roessingh, Enschede; <sup>12</sup> Klimmendaal, Arnhem; <sup>13</sup> Libra, Eindhoven; <sup>14</sup> Adelante, Valkenburg.

\* Centers with multiple locations: Only the primary/largest location is shown.

## AIMS OF THIS THESIS

**Section 1** presents the results of the “Participate?!” project regarding **persisting consequences of ABI in young individuals and families referred to outpatient rehabilitation in the Netherlands**. The aim of this section was to describe the course and/or severity of HRQoL, fatigue, participation, and family impact in young people with ABI and their families referred to outpatient medical specialist rehabilitation.

**Chapter 2** introduces a new way to categorize and interpret fatigue severity levels among young patients with ABI based on scores from healthy age-matched peers. **Chapter 3** presents the results of a two-year follow-up study on fatigue and participation in children and young adults with ABI in the outpatient rehabilitation setting. **Chapter 4** comprises a study on participation restrictions in an outpatient rehabilitation cohort and explores the differences in participation perspectives between patients with ABI and their parents. **Chapter 5** describes parent-reported family impact at the time of referral to outpatient rehabilitation among families with a child with ABI and identifies factors that negatively influence family impact. **Chapter 6** focuses on the course of family impact and quality of life over a two-year period among parents of young patients with ABI. For the purpose of this thesis, patients’ caregivers are also referred to as ‘parents’.

**Section 2** of this thesis presents the results of the “Participate?! Next Step” project concerning **joint collaborations between rehabilitation centers to optimize care for young individuals with ABI**. This section aims to describe and compare the structure and process of rehabilitation for young patients with ABI across Dutch rehabilitation centers. Furthermore, it aims to describe the development a national consensus-based framework for clinical practice, including preferred assessments, interventions, and psychoeducation, for young people with ABI across Dutch rehabilitation centers. **Chapter 7** describes potential variations among Dutch Rehabilitation Centers in the structure of rehabilitation care i.e., admission and discharge criteria, the organization of care, and the aftercare for young patients with ABI. **Chapter 8** concerns a Delphi study among healthcare professionals from 14 rehabilitation centers to reach a consensus on the content (assessments, interventions, and psychoeducational materials) of a national framework based on current practices for young people (4-25 years old) with ABI and their families in the Netherlands.

In **Chapter 9**, the findings of the studies in **Sections 1 and 2** are summarized and discussed.

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