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Participation of children and youth with acquired brain injury

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Chapter 8
Summary and general
discussion



SUMMARY

Aims of the thesis

Paediatric acquired brain injury (ABI) is a major public health issue¹ and often results in pervasive, lifelong consequences for the child and his or her family. The literature suggests that the long-term consequences of paediatric ABI, in particular with respect to participation, are underestimated, poorly understood and managed.² Given this lack of knowledge, this thesis aimed

- To determine the occurrence and causes of ABI in children and youth in the Netherlands (chapters 2 and 3).
- To systematically review the literature on factors associated with participation in children and youth with ABI (chapter 4).
- To translate, adapt and validate an instrument to measure participation after paediatric ABI into the Dutch language (chapter 5).
- To evaluate the family impact in a cohort of children and youth with ABI and their family (chapter 6).
- To explore the potential effect of virtual reality (gaming) on physical, cognitive and social functioning of children and youth with ABI (chapter 7).

Main findings

Chapter 2 concerned a retrospective, multi-centre cohort study on the occurrence and causes of acquired brain injury (ABI), including traumatic brain injury (TBI) and non-traumatic brain injury (NTBI), among Dutch children and youth.

For this purpose patients, aged 1 month-24 years and diagnosed with ABI in 2008 or 2009, were identified from the registries of three hospitals. 1892 patients were included: 1476 with TBI and 416 with NTBI. With respect to severity, the large majority of cases were mild: 82.4% and 81.4% in TBI and NTBI groups, respectively.

Based on these figures, the estimated total relative incidence rates of TBI and NTBI per 100 000 per age groups were 271.2-15.4-2.3 (0-14 years) and 261.6-27.0-7.9 (15-24 years) for mild-moderate-severe TBI and 95.7-11.8-1.3 (0-14 years) and 73.8-6.1-1.6 (15-24 years), for mild-moderate-severe NTBI, respectively.

In patients with TBI aged 0-4 years, accidents in or about the family home were the most common, whereas in patients aged 5-14 and 15-24 years, traffic accidents were the most frequent cause. With respect to the causes of NTBI meningitis and encephalitis were relatively frequent in the 0-4 year old group, whereas brain tumours showed a peak in the 5-14 year old group. Stroke occurred with a relatively similar frequency in the three age groups.

Based on the same retrospective cohort study, *Chapter 3* described clinical characteristics and medical treatment in patients, aged 1 month-24 years, who presented with a traumatic

brain injury at one hospital in the Netherlands in 2007 and 2008. 472 patients met the inclusion criteria; severity of the injury was classified as mild in 342 (72.5%) patients, moderate in 50 (10.6%) patients and severe in 80 (16.9%) patients.

Of all included patients, 343 (72.7%) were admitted to the hospital. The medium length of stay was 7 days, 3 days and 1 day in patients with severe, moderate and mild TBI, respectively. In patients with severe TBI a significantly larger number of complications occurred during the clinical course than in patients with mild or moderate TBI. Twenty-four (5.1%) patients died, of whom 22 had a severe TBI.

In 398 patients (84.3%) a brain CT (computer tomography) scan or MRI (magnetic resonance imaging) scan was performed, with 78 of them (19.6%) having a normal brain CT scan. The latter contributed to the decision to discharge them to their home. 107 (22.7%) patients with TBI received no hospital follow-up care after discharge. Patients with severe TBI significantly more frequently received outpatient treatment after discharge, in particular rehabilitation, as compared to patients with mild or moderate TBI. 24 (16.7%) of the patients with mild TBI patient had follow-up and were reporting long-term cognitive impairments, whereas 60 (42.0%) of these patients had no abnormalities on brain CT scan at admission. This latter finding supports the need for routine follow up of children and youth with mild TBI.

Chapter 4 concerned a systematic review on the determinants of participation of children and youth with ABI. Employing the usage of a recommended, explicit participation outcome measure as one of the inclusion criteria for this review, five clinical studies were selected. The measures of participation included in these studies concerned the Child and Adolescent Scale of Participation (CASP) and the Children's Assessment of Participation and Enjoyment (CAPE). Potential determinants of participation were categorized according to the International Classification of Functioning, Disability and Health (ICF). The factors which were found to be most consistently associated with one or more dimensions of participation (defined as a similar (positive or negative) relation found in more than 1 study and not disputed in another study) were: severity of ABI; sensory functioning (Health Condition); movement functions, cognitive and behavioural functioning (Body Functions and Structures); accessibility and design of the physical environment, acceptance and support from other people, socioeconomic status and availability of special services and programmes (Environmental Factors).

Chapter 5 described the process of translation and adaptation of the questionnaire for parents of the Child and Family Follow-up Survey (CFFS), developed to monitor the long-term outcomes of children and youth with ABI. The CFFS consists of 3 subscales, the Child and Adolescent Scale of Participation (CASP), the Child and Adolescent Factors Inventory

(CAFI), and the Child and Adolescent Scale of Environment (CASE). After translation and adaptation, the psychometric qualities of the CFFS-Dutch Language Version (DLV) were determined among 147 patients with ABI, from 2 up to 3 years after onset of injury. Most of these patients were participants of the cohort study described in chapters 2 and 3.

This study showed that all three subscales of the CFFS-DLV proved to be reliable and valid instruments to measure long-term outcomes of children and youth with ABI. The internal consistency of the 3 subscales was high, with Cronbach's alpha being 0.95 for the CASP-DLV, 0.89 for the CAFI-DLV and 0.83 for the CASE-DLV. Moreover, there were significant mutual correlations among the CASP-DLV, CAFI-DLV and CASE-DLV, underlining the value of the CFFS-DLV in determining and understanding associations between extent of participation (CASP), extent of impairment (CAFI) and environmental barriers (CASE).

In *Chapter 6* the impact of ABI on the family of the child as well as its determinants were studied in connection with the cohort study described in chapters 2 and 3. Two to 3 years after onset of ABI, family impact was measured by means of the Paediatric Quality of Life Inventory Family Impact Module (PedsQL™FIM) in 108 children. Their age ranged between 5 and 22 with a median age of 13 years old, 81 (75%) had TBI and 27 (25%) NTBI. The condition was classified as mild, with the patient experiencing no or few consequences, in 62 (77%) of the patients with TBI and in 22 (81%) of the patients with NTBI. Overall, the impact on the family after the paediatric ABI was considerable. Multivariable analysis showed that the severity (moderate/severe>mild) and type (NTBI>TBI) of ABI and the presence of health problems before the injury occurred were associated with a higher family impact (Total Score on the PedsQL™FIM). The PedsQL Family Impact Module seems to be a useful instrument in this patient group.

Chapter 7 explored the effects of usage of the Nintendo™Wii on physical, cognitive and social functioning in youth and adolescents with ABI. In this proof-of-concept, observational study 45 patients aged 8 up to 30 years old were included, with 35 (78%) of them longer than 2 years after onset of their condition and 22 (49%) having TBI.

The 12-week intervention consisted of the assignment of three computer games to every patient, matching the individual and self-chosen treatment goals and taking into account the individual's motor and cognitive limitations and interest. After 2 instruction sessions, patients were encouraged to play games for at least 20 minutes per day and/or 2 hours per week. Trained therapists/teachers had weekly contact with the participants by e-mail or telephone. Assessments were done at baseline and after 12 weeks. It was found that physical activity, the speed of information processing, attention, response inhibition, and parent-perceived Quality of life (QoL) were improved directly after the intervention. Two-thirds of the patients

reported an improvement of their individualized treatment goal. No differences over time were seen for patient-perceived QoL and participation in leisure activities.

GENERAL DISCUSSION

ABI in children and youth in the Netherlands: occurrence, terminology and hospital policy

The results of the studies included in this thesis suggest that the incidence of ABI in children and youth is considerable. Moreover, it was found that relatively many have long-term health problems, including limitations in psychosocial functioning, participation and QoL and that the impact on their families is substantial. These findings underscore the need for an increasing awareness for the impact of paediatric ABI. According to the 'Good Practice Recommendations' of the International Paediatric Brain Injury Society³ "there must be an increased awareness and recognition that ABI can affect young people throughout the course of their development up into adulthood, provoking changing and emerging needs". Moreover, these recommendations stated that "there must be further education of medical practitioners and teachers, especially regarding cognitive and behavioural consequences which can be overlooked in comparison to those affecting motor function".³ Ralph⁴ systematically reviewed literature on knowledge, (mis)conceptions and attitudes towards survivors of ABI. She concluded that, despite the observation that public knowledge increased over the last 25 years, there are a number of common misconceptions (such as a complete recovery can be achieved by all survivors and (speed of) recovery is dependent on patients' effort), that may result in decreased acceptance and support by professionals as well as family and friends. ABI is defined as 'any post-neonatal damage to the brain, due to an external cause (traumatic brain injury, TBI) or internal cause (non-traumatic brain injury, NTBI)'. However, there is confusion about the terminology: a) ABI is used for a wide variety of diagnoses and as an umbrella concept for an even larger variety of possible consequences.⁵ It has therefore been suggested to use "ABI" for the overall diagnosis and reaching consensus about a more specific definition of TBI⁶ and NTBI⁷, using the International Classification of Diseases (version 10) codes⁸. In addition, consequences of ABI should probably not be called ABI but should be defined more specifically, according to the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY). For example: a 17 year old adolescent who had a subarachnoid hemorrhage (ICD 60.3) at the age of 12 years old, may have visual field loss (ICF b2101), impaired quality of vision (b2102), problems with reading (d166) and failed to pass an entry assessment in higher professional education (d8250). Regarding the classification of severity of paediatric ABI, different systems are used for TBI and NTBI. Severity of paediatric TBI is usually determined by the GCS score, but the literature on its predictive properties for the outcome is conflicting⁹. Classification of the

severity of paediatric NTBI is usually done by the mRS, although this measure has not been validated for all potential causes of NTBI.¹⁰

The differences in the classification systems for severity within and among TBI and NTBI suggest that conclusions on the relationship between severity and long-term outcomes should be interpreted with caution, which applies to the results presented in this thesis as well. It remains to be established to what extent a combination of an appropriate set of neuroimaging (MRI) and age-specific clinical and neuropsychological assessments may improve the early classification of severity of children and youth with ABI. Neuropsychological testing in the initial post-injury phase appears to have additional predictive value with respect to the short and long-term outcome, enabling prompt treatment, follow-up or referral if needed, thereby compounding long-term disabilities and reducing health care costs.¹¹ A risk index including the health status of the child and family before ABI has also been suggested as a means to structure an efficient triage and follow-up, especially for the mild TBI group.¹²

Concerning the *registration* of the diagnosis ABI and its severity, our study with medical records of patients with a hospital based diagnosis of ABI found that registration was often incomplete (e.g. registration of Glasgow Coma Score, modified Rankin Scale, suspicion physical abuse). This observation underlines the need for consistent implementation of guidelines, e.g. 'Care of patients with mild traumatic head/brain injury'.¹⁰

Furthermore, variation in the clinical management (admission or not, length of stay, usage of CT or MRI, and the scheduling of follow-up) of patients with TBI presenting at one hospital was found in our study as well. A larger, prospective study is however required to draw more valid conclusions on potential variability in hospital policies after TBI.

Prevention is probably the best intervention for ABI. We found that the causes of TBI differ strikingly among age categories, a finding that can be used when considering preventive measures, like appealing and age-specific education for children, youth, parents and caregivers, health care providers and teachers. This education could e.g. include signs and symptoms of abusive head injury or the risk of TBI as a direct (drugs affecting brain functions) or indirect (causing accidents and abuse) result of alcohol and drug abuse. Regarding TBI, the relatively high percentage of accidents in and around the house in the 0-4 years group and the relatively high percentage of (suspicion of) physical abuse in the age group 15-24 years, as seen in the study presented in Chapter 2 and 3, was notable. Raising awareness in children and youth, parents and caretakers of risk factors for TBI is warranted, such as adequate fixation in a car seat, chair or stroller or helmets for children in traffic. Vulnerability of the developing brain should be addressed in primary and secondary education. Tailor-made education and support could also be an effective intervention to decrease the burden of NTBI.¹⁴

Participation of children and youth with ABI and families

Children and youth with ABI are at risk for participation problems, both in the stages of recovery as well as later on. A 'double hazard' effect has been reported, where social disadvantage with severe injury leads to poorest long-term outcome.¹⁵ Participation is the most relevant outcome of recovery and main goal of rehabilitation. However, a better general understanding and improvements of assessment and treatment are required to decrease the impact of paediatric ABI on participation of youth and their families.

Recommendations based on this thesis are: a) implement the ICF-model to improve comprehension of participation (problems) after paediatric ABI; b) measure and monitor participation after paediatric TBI and NTBI and c) develop and evaluate trajectories optimising participation.

a) The ICF-CY model¹⁶ is a suitable model to demonstrate the complex, interrelated and dynamic nature of participation of children and youth in relation to the specific nature and impact of paediatric ABI. Figure 1 shows a proposal for a 'participation model', based on the results of the systematic review on determinants of participation in ABI (Chapter 4).

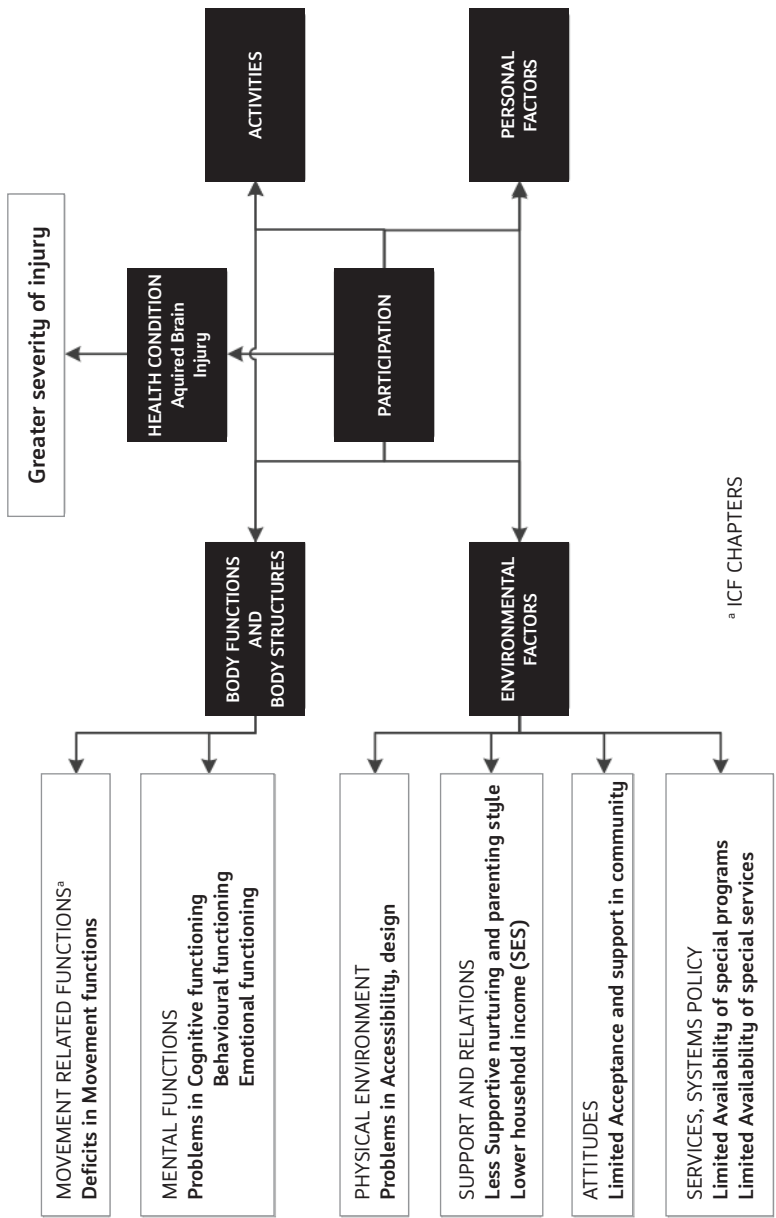
The proposed model could probably be discussed and refined in focus groups with patients with ABI, parents and professional experts. This should preferably be done separately for TBI and NTBI, in order to improve understanding of participation in these two different forms of ABI.

b) Improvement of the assessment and monitoring of participation (in patients) and of QoL (in patients and parents) in paediatric TBI and NTBI is needed. This may on the one hand increase the understanding of (factors associated with) participation outcomes in paediatric ABI, and on the other hand enable the evaluation of interventions such as rehabilitation programmes. The CASP-DLV and CASE-DLV are promising instruments in this respect, which could probably be combined with the PedsQL HR QL (Chapter 5), in particular since all three are recommended as outcome measure in ABI.¹⁷

Ideally, participation is monitored at different time points and on the long-term (Chapter 4). Families with a child with ABI should be monitored regarding the impact of the condition as well, for which aim the PedsQL Family Impact Measure (FIM) seems a suitable instrument (chapter 6). The assessment of the health-related quality of life of parents, included in the FIM, is indicative for their healthcare needs. Implementation of these instruments in Dutch outpatient clinics for rehabilitation care should be considered using the results of follow-up studies to determine which groups 'at risk' for a worse outcome should be monitored on a structural basis.

c) Development and evaluation of interventions specifically for paediatric ABI. The literature on participation in ABI suggests that interventions should be: early, targeted and tailor-made¹⁸, connected and well-coordinated¹⁹, highly specialised² and with longitudinal follow-up through developmental stages.²⁰

Figure 1 Participation model



Based on: World Health Organization, 2007

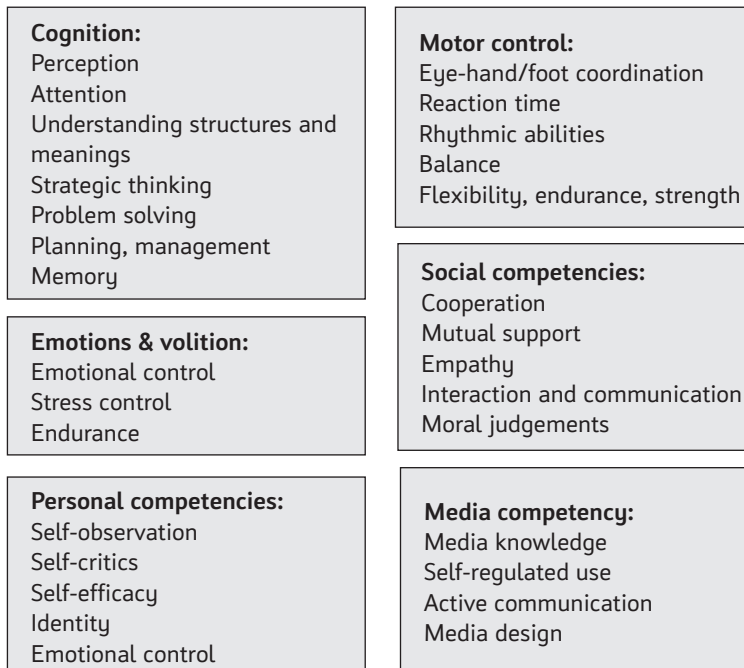
Hospital, rehabilitation and chronic care should be connected, with overlapping programmes and anticipating planning. Currently, parents express dissatisfaction with inadequate service provision, lack of information about ABI and its consequences, waiting times, not knowing where to find appropriate services, and services not adapting to the needs of child and family changing over time.¹⁹ Family factors (functioning, socioeconomic status (SES), family burden) and other aspects of the child's environment (peers, school/work, leisure time) are related to participation and should be addressed in comprehensive rehabilitation programmes. In the recent literature on paediatric ABI and in daily practice there are a number of examples of how the abovementioned recommendations can be put into practice. These examples currently constitute 'practice based evidence' and need to be further evaluated regarding their effectiveness.

1. The Dutch language version of the Brain Stars programme²¹ concerned the development of a tailor-made, comprehensive, practical manual for parents and teachers, aiming to educate parents and professionals about pediatric ABI and enhance better understanding and management of its consequences. It includes background information about ABI, related to child and adolescent development, recommended interventions, and worksheets.
2. Hersenletsel en Jeugd (HeJ),²² a Dutch national project that started in 2011, aims to outline targets for improving paediatric ABI-pathways. HeJ is organized in 6 task forces (acute care-rehabilitation-chronic care-school and work-development - and research), and has resulted in a school protocol for students with ABI, a tool box for family support and enhanced collaboration in research projects.²² HeJ organises an annual, national symposium for professionals in health care and primary and secondary education to share and disseminate knowledge and special services, programmes and policy.
3. Recently an app, the 'Activiteitenweger' has been developed, to monitor daily activities of people with restrictions in their daily activities as a result of pain and/or fatigue, a common complaint after ABI.²³
4. An example of evidence based practice is the family-supported rehabilitation of children with TBI in Sarah network of rehabilitation hospitals in Brazil,²⁴ incorporating the parents, teachers and family into the rehabilitation process.
5. The project 'Friends4Friends' aims to enhance participation of children and adolescents with ABI in recreational time, by means of buddy support by students.²⁵ Apart from the support of individual patients, it aims to increase awareness and competences of students in professional education. A similar effect is pursued in the project 'Brains4U', embedding managers in a vocational rehabilitation intervention aiming to get paid employment in adolescents and young adults with ABI.²⁶ 'See potential, not potential problems' is a stimulating slogan in both projects, influencing environmental factors with respect to participation of people with ABI.

The potential of gaming to improve physical, cognitive and social functioning of children and youth with ABI

This thesis evaluated the potential benefits of gaming in patients with ABI (Chapter 7). By providing enhanced environmental stimulation and augmented information to the user, gaming may increase motivation, adherence, and duration or intensity of exercises and the practices of skills. Gaming offers unique opportunities in the rehabilitation of children and youth with ABI as it meets several requirements posed by theories of learning²⁷ and neurorehabilitation:²⁸ training is most effective when it is active, intensive, experiential, tailor-made, situated, functional, problem-based and provides immediate feedback. Therefore, it is more and more acknowledged that gaming is a useful addition to or alternative for conventional therapeutic interventions aiming to improve learning and performance of motor skills (e.g. gait, static and dynamic balance, bimanual training, movement and energy expenditure), cognitive skills (e.g. attention, response inhibition, visual-perceptual and speed of processing, communication) and socio-emotional skills (e.g. playfulness, motor confidence, self-control and management) in the rehabilitation of children, youth and adults with ABI.^{29,30} Gaming could have an effect competencies as shown in Figure 2.³¹

Figure 2 Competencies potentially enhanced by playing digital games



From: Wiemeyer & Kliem³⁰

Game technology rapidly improves, with the international organisation 'Games for Health'³² aiming to bring healthcare together with the serious gaming industry. The 'off-the shelf' console Nintendo Wii (first release November 2006) enables the performance of whole-body movements and social play. The Microsoft Kinect (first release November 2010, last upgrade in January 2014) enables gaming without the need to physically touch a game controller, it can detect a person's location in 3-D (three-dimensional) space and it can register full-body, head to feet motions more precise. Recent improvements in applications are the development of specific rehabilitation games,³³ the adaptation of consoles in order to adjust to specific motor or cognitive demands, to better focus on quality of movement and influence therapeutically relevant aspects of motion³⁴ and the design of a personalized virtual environment, e.g. walking at home or biking in a patient's own neighbourhood.³⁵ Apart from gaming, the use of other technological applications in rehabilitation increases, examples being telemedicine, the use of computer tablets and smartphones. In this rapidly developing area of practice stakeholders (patients, health care providers, developers, manufacturers, researchers) should probably share their needs and knowledge and collaborate in consortia for the further development, evaluation and implementation of technology in rehabilitation. Collaborations between rehabilitation centres, hospital departments of rehabilitation, (technical) universities and universities of applied sciences and industries is needed to further develop and test gaming and ICT application. The Dutch taskforce 'E-rehabilitation' initiated such a process in Dutch rehabilitation and organized a national symposium in March 2014.

Directions for future research

Registration of data on the incidence and causes of TBI and NTBI in children and youth in a national database is necessary. Only by means of a standardized registry, including all relevant clinical data, based on ICF-categories (Chapter 2,3), and using the electronic registration systems of Dutch hospitals and rehabilitation centres, valid conclusions on the occurrence and outcomes of TBI and NTBI can be made. Further research should preferably be done in patients with mild TBI, by far the largest group of new patients. About 10-20% of youth with mild TBI report significant, ongoing problems impacting adversely participation at home, school or work and in other social relations and interactions. Therefore, research should focus on determinants of outcome and the effectiveness of early interventions in this specific group. Thereby, prediction models for decision making in the (post) acute phase and follow-up can be made, including the appropriate triage to select patient at risk, effecting health status as well as health care and societal costs.

Further research is also suggested with respect to participation of children and youth with ABI, to decrease the current knowledge gap regarding participation outcomes. This will facilitate the evaluation of rehabilitation programmes with respect to participation outcome, including

generalisability in everyday life. A prerequisite for such research is that consensus regarding the definition of participation, the usage of recommended, explicit participation outcome measures and the set of potential determinants to be analysed is attained. Moreover, studies should include large cohorts of children and youth in all age groups and different causes and severity of the injury and should employ a methodologically sound analysis (Chapter 4).

It is further recommended to follow existing guidelines regarding the development of participation measures, pertaining to: a) Definition of the aim of measuring: description (e.g. activities, time, patterns, limitations), discrimination (differences between groups) or evaluation (change over time);³⁵ c) Employing mixed methods research, combining quantitative and qualitative data;² d) Inclusion of environmental factors, differentiation regarding in sub domains with specific aspects of participation (e.g. social interactions at work) and differentiation regarding age (e.g. play of younger children).³⁶

Regarding the treatment of patients with ABI, larger, controlled studies on the effect of computer games on motor, cognitive and socio-emotional functions are required. Concerning the measurement of their effectiveness, assessments should preferably include imaging techniques such as functional Magnetic Resonance Imaging (fMRI) and be focused on the transfer of trained tasks to activities in daily life, participation and quality of life.

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