Participation of children and youth with Acquired Brain Injury
Summary of PhD Thesis by Arend de Kloet

Acquired brain injury (ABI) in children and adolescents is a major public health problem by the enduring consequences[1] for the child and the family in which he is growing up. The literature suggests that brain injury in children and young people and the long-term consequences, particularly with regard to participation for children and families are underestimated, poorly understood and remain neglected in research.[2]

This thesis therefore aims:
a. To determine the incidence and the causes of brain injury in children and adolescents;
b. To conduct a systematic review of factors associated with participation of children and young people with brain injury;
c. To translate a specific target audience participation questionnaire to the Dutch language and to investigate the psychometric qualities;
d. To determine the impact of brain injury on families of children and adolescents;
e. To explore the potential impact of serious gaming on the physical, cognitive and social functioning of children and adolescents with ABI.

The thesis contains four studies, in which the above five research questions are answered. The main findings (Chapters 2-7), are summarized below.

Chapter 2 of this thesis describes a retrospective, multicenter cohort study into the incidence and causes of brain injury, both with a traumatic (Traumatic Brain Injury TBI) as a non-traumatic cause (Non-Traumatic Brain Injury, NTBI) in children and youth in the Netherlands.
For this purpose, patients aged 1 month to 24 years, with a brain injury diagnosis in 2007, 2008 or 2009, where selected from the records of three hospitals in The Hague and Rotterdam. A total of 1892 patients were included, 1476 of them with TBI and 416 with NTBI. The classification of severity of the injury in the majority of the group was "light", namely 82.4% in the TBI group and 81.4% in the NTBI group. Based on these figures and an estimate of the number of residents in the service areas of the hospitals, the relative incidence of TBI and NTBI per 100 000 inhabitants were extrapolated: for light to moderate TBI this was 271.2-15.4-2.3 respectively (age 0 to 14 years) and 261.6-27.0-7.9 (age 15 to 24) and light-moderate NTBI this was respectively 95.7-11.8-1.3 (age 0 to 14 years) and 73.8-6.1-1.6 (age 15 to 24).

In the age group of 0 to 4 years, TBI was mainly due to accidents in or around the house, whereas in the groups of 5 to 14 and 15 to 24, accidents were the most common cause. Meningitis and encephalitis were relatively common cause of NTBI in the group of 0 to 4 years, while two brain tumors were found to be a major cause in the 5 to 14 year group. A stroke was comparable common in the three age groups. Based on the same retrospective cohort study, Chapter 3 focuses on the clinical characteristics of the Rotterdam cohort of patients aged 1 month to 24 years old, who were registered with traumatic brain injury (TBI) in 2007 and 2008 in one hospital. This chapter also describes the intended hospital policy for this group. 472 patients met the inclusion criteria, the severity of the injury was light in 342 (72.5%), moderate in 50 (10.6%) and severe in 80 (16.9%) of these patients. Of this group 343 (72.7%) children and young people were hospitalized. After severe traumatic brain injury, the average hospital stay was seven days, after moderate traumatic brain injury it was three days and after mild traumatic brain injury one day. For patients with severe TBI considerable complications occurred. 24 patients died, 22 of them after a severe TBI. In 398 patients (84.3%) a CT scan or MRI scan of the brains was performed, in seventy-eight of them (60%) no abnormalities were found and they were discharged home. Data on the long-term effects were generally incompletely recorded in the medical records. After discharge no follow-up appointment was made for 107 (23%) patients with TBI. Patients with severe TBI were significantly more frequently referred to an outpatient treatment program, especially for outpatient rehabilitation, than patients with moderate or mild TBI. Almost 17% of the group with mild TBI exhibited cognitive limitations at follow-up, whereas for 42% of them no abnormalities in the CT scan were found at hospitalization. This finding supports the discussion about the need for a careful and efficient follow-up of children and young people with traumatic brain injury, even if the injury is light.

Chapter 4 presents the results of a systematic review of the determinants of participation in children and adolescents with brain injury: five studies were selected that reported an explicit participation measure of outcome and met the other inclusion criteria.
These five studies showed that 12 to 84 months following the occurrence of brain injury, 25 to 80% of children and young people were limited in at least one participation area (home, school or in the community), while the participation problems barely decreased over time. Factors that were associated most consistently with participation (defined as a similar result in at least two studies and no conflicting results between studies) were: more severity of the injury, sensory problems (ICF component body functions and structure); difficulties in motor function, cognitive or behavioral function (component body functions and structure), presence of problems in the accessibility and design of the physical environment and the lack of social acceptance and support. Higher social economic status and the availability of special services and programs (component external factors) scored consistently positively associated with participation.

Chapter 5 deals with the process of translation, adaptation and validation of the Child and Family Follow-up Survey CFFS-DLV (Dutch Language Version), developed as a questionnaire for parents to measure the long-term effects of brain injury in children and young people and monitor the participation. The CFFS consists of three subscales: the Child and Adolescent Scale of Participation (CASP-DLV) measures the actual participation of the child at home, at school and in society. The Child and Adolescent Factors Inventory (Cafi-DLV) gives an overview of the child's characteristics. The Child and Adolescent Scale of Environment (CASE-DLV) identifies the environmental factors that affect the participation. The psychometric properties of the CFFS-DLV were determined in 147 patients with brain injury, two to three years after the occurrence of the injury. Most of the patients in this cohort were included in the retrospective cohort study (Chapter 2 and 3). The three subscales of the CFFS-DLV all proved reliable and valid instruments to measure the three long-term effects of brain injury on the participation of children and young people. The internal consistency of the three subscales was high, with Cronbach's alpha 0.95 for the CASP-DLV, 0.89 for the cafs-DLV and was 0.83 for the CASEDLV. Moreover, we found significant correlations between the subscales CASP-DLV, cafs-DLV and CASEDLV themselves, so the added value of the CFFS-DLV in identifying and understanding relationships between the degree of participation (CASP-DLV) and limitations experienced by parents of the child (Cafi-DLV) and the environment (CASE-DLV) has been emphasized.

In Chapter 6, the impact of brain injury on the family is described, also based on the retro-spective cohort study (Chapter 2 and 3). We also examined the factors that primarily determine the impact on the family. Two to three years after the occurrence of the NAH family impact was measured using the Pediatric Quality of Life Inventory Family Impact Module (PedsQL ™ FIM DLV). The families of 108 children, of which a relatively high percentage had a slight TBI showed the measured impact on family to be significantly. Multivariate analysis showed that the severity (moderate-severe-mild) and the cause (NTBI - TBI) of the injuries were associated with greater family impact (total score on the PedsQL ™ FIM) and the presence of health problems before the injury arose. The PedsQL Family Impact Module appears to be an adequate instrument to measure impact on family and family functioning after brain injury to a child or young person.

Chapter 7 evaluates the potential impacts of gaming with the Nintendo Wii ™, a console with mainly motor games, on physical, cognitive and social functioning of children and adolescents with brain injury. 45 children, all youth and young adults with brain injury, aged 8 to 30 years, participated in this proof-of-concept observational study. The majority of the group was no longer in rehabilitation treatment. In 35 (78%) of them, the injury occurred more than 2 years before the intervention. In 22 (49%), there was traumatic brain injury (TBI). The intervention which lasted twelve weeks, consisted of playing three games, the choice of which had been tailored to the patient, in keeping with the latter's self-selected treatment goals and taking into account the individual motor and cognitive impairments and interest. After two instruction sessions (by therapists and teachers), the patients were encouraged to play games at least 20 minutes a day or 2 hours a week. Hereby they were supported by therapists, by maintaining a weekly contact by email or phone. At the end of intervention there was, as compared to before the treatment, an increase of the amount of physical activity, improvement of the speed of information processing, attention, response inhibition and improved quality of life (perceived by parents). Two thirds of the patients reported an improvement in their self-determined goals. There was no improvement on quality of life and leisure experienced by the patients themselves.

REFERENCES

1. World Health Organization. World report in child injury prevention. Geneva: World Health Organization 2008.whqlibdoc.who.int/publications/2008. Date accessed 08-08-2013.
2. Van Tol E, Gorter JW, DeMatteo C. Participation outcomes for children with acquired brain injury: A narrative review. Brain Injury 2011;25:1279-128