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

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CHAPTER 9

Summary and general discussion

SUMMARY

Acquired Brain Injury (ABI) refers to any damage to the brain that occurs after birth caused by either Traumatic Brain Injury (TBI) or Non-Traumatic Brain Injury (nTBI).[1] ABI is a relatively common condition in Dutch children, adolescents, and young adults aged between 4 and 25 years old.[2,3] It can have significant and persisting consequences across various health domains.[2,4-7] When the impact of ABI is substantial, it may necessitate inpatient or outpatient medical specialist rehabilitation in a rehabilitation center.[2,8-10] This thesis aimed to enhance the understanding of ABI-related consequences and optimize the quality of rehabilitation provided to young individuals with ABI in the Netherlands by addressing the following overarching research questions:

First, to describe the course and/or severity of Health-related Quality of Life (HRQoL), fatigue, participation, and family impact in young people with ABI and their families referred to outpatient medical specialist rehabilitation between referral and one and two years later.

Second, to describe and compare the structure and process of rehabilitation for young patients with ABI across Dutch rehabilitation centers and develop a national consensus-based framework for clinical practice, including preferred assessments, interventions, and psychoeducation, for young people with ABI across Dutch rehabilitation centers.

Chapter 1 provides a general, comprehensive overview of ABI in young individuals aged 4-25 years. It covers key aspects, such as definitions, epidemiology, consequences, and stages of recovery, and current management, with a focus on medical specialist rehabilitation.

Furthermore, this chapter introduces the background of two research projects that have contributed data to the studies within this thesis. The first project, entitled “Participate?!”, concerned a cohort study conducted in ten Dutch rehabilitation centers. This project systematically collected data from consecutive patients with ABI and their parents on various domains of functioning over time. The second project, “Participate?!” Next Step included a mixed-methods study among healthcare professionals from 14 Dutch rehabilitation centers. This multifaceted project utilized a cross-sectional survey study to investigate the occurrence of practice variation across rehabilitation centers and to develop a national framework with preferred assessments, interventions, and psycho educational materials in pediatric ABI rehabilitation practice.

Section 1. Persisting consequences of ABI in young individuals and their families referred to outpatient rehabilitation in the Netherlands

In this thesis the persisting consequences after ABI among young individuals are described, specifically focusing on the International Classification of Functioning, Disability and Health (ICF) domains *'body functions and structures'* (**Chapters 2 and 3**), *'activities and participation,* (**Chapter 4**), and '*environmental factors*', (**Chapters 5 and 6**). The data used in the studies described in **Chapters 2-6** were gathered by means of a multicenter cohort study (Project "Participate?!"). Over a four-year period, ten rehabilitation centers gathered data from consecutive patients with ABI between 5-24 years old and their parents at admission (baseline) and one and two years later. Patient-Reported Outcome Measures (PROMs) were used to assess various health domains, including Health-Related Quality of Life (HRQoL), fatigue, participation restrictions, and family impact. Specifically, the following PROMs were employed: the Pediatric Quality of Life Inventory™ Generic Core scales-4.0 (PedsQL™ GCS-4.0),[11-13] the PedsQL™ Multidimensional Fatigue Scale (PedsQL™ MFS),[14-16] the Child and Adolescent Scale of Participation (CASP),[17,18] and PedsQL™ Family Impact Module (PedsQL™ FIM).[19] In addition to these PROMs, a questionnaire was administered to collect data on demographics, injury specifics, patient characteristics, and family related factors. At baseline 223 young patients and 246 parents were included. From 94 patients and 104 parents, data was available at follow-up at either one year (T1), two years (T2), or both. The number of patients and parent may vary for the different analyses as the proportions of patients and parents completing specific instruments varied both within and across time points.

Chapter 2 described the extent of fatigue in young patients with ABI following outpatient rehabilitation using the PedsQL™ MFS as completed by patients and parents at baseline. For this cross-sectional analysis, the total score and subdomain scores to capture general fatigue, sleep/rest, and cognitive fatigue from the PedsQL™ MFS were used (scores ranging from 0 to 100, lower scores indicating higher fatigue levels). Additionally, the severity of fatigue was categorized using previous data from two studies with healthy Dutch peers to create cut-off scores. The mean fatigue scores and their corresponding standard deviations (SD) from healthy peers were used to quantify the number of standard deviations by which the patients in our cohort deviated from the mean scores of healthy peers. Based on the total scores of the study participants and the data from healthy peers four severity categories of fatigue scores were distinguished:

1: scores more than +1SD difference (less fatigued compared to healthy peers),
2: scores between +1SD and -1SD (fatigue comparable with healthy peers),
3: scores between -1SD and -2SD (moderately more fatigued),
4: scores with more than -2SD difference (severely more fatigued than healthy peers).

Findings showed that patients with ABI and their parents reported considerable fatigue, with mean (SD) patient-/parent-reported PedsQL™ MFS total scores of 51.0 (17.3)/ 53.5 (19.2), respectively. These scores were significantly lower than those of healthy peers, which ranged between 71.8 (14.6) and 82.1 (17.8). Fifty to 88% of the young patients with ABI either scored in the “moderately more fatigued” or the “severely more fatigued” categories. It was concluded that categorizing fatigue severity cut-off scores appeared to be a suitable tool for monitoring fatigue. This categorization could be used next to the linear scores from the PedsQL™ MFS.

In **Chapter 3**, the course of fatigue and participation and their relationship over time were assessed. For this longitudinal observational study, the PedsQL™ MFS and CASP from the same cohort were used. Linear mixed models were used to assess the changes in fatigue and participation scores over time (change scores, (95% CI), p-values) and repeated measures correlations were used to describe correlations (r_{rm}, (95% CI), p-values) between fatigue and participation over time. 223 patients and 246 parents completed the questionnaires at baseline, whereas 94 patients and 104 parents completed the same questionnaire at T1, T2, or both time points. Patient-reported fatigue and participation scores improved significantly between baseline and T2 (+8.8, (2.9-14.7), $p < 0.05$ and +10.5, (6.3-14.7), $p < 0.05$). Comparable results were found regarding parent-reported fatigue (+8.7, (3.4-13.9), $p < 0.05$), but not for participation (+3.9, (1.1-7.7), $p > 0.05$). Fatigue scores were relatively low at baseline and fatigue remained considerably present two years after referral to rehabilitation. A moderately strong longitudinal correlation between patient-reported PedsQL™ MFS and CASP scores over time (r_{rm}=0.7, (0.6;0.8), $p < 0.001$), and a fair correlation for parent-reported data (r_{rm}=0.5, (0.3;0.6), $p < 0.001$) was found. These findings suggest that increased fatigue can lead to more participation restrictions at all time points. Despite the improvements over time, patients were still more fatigued than their healthy peers, and participation remained limited.

Participation restrictions among young patients with ABI and the differences between the patients’ and parents’ perspectives are described in **Chapter 4**. For the purpose of this cross-sectional study using data from the same cohort that was described in previous chapters, CASP scores were classified into four categories:
1: scores between 100–97.5 (full participation),
2: scores between 97.5–81.0 (somewhat limited participation),
3: scores between 81.0–68.5 (limited participation),
4: scores below ≤ 68.5 (very limited participation).

Considerable participation restrictions were found. Parents -reported significantly less participation restrictions compared to patients (91.3 (IQR: 80.0-97.5) vs 82.5 (IQR: 67.5-90), $p < 0.05$). In particular young adults tended to rate their participation worse than parents. A notable proportion of patients (n=58, 26%) and parents (n=25, 10%) reported scores reflecting “very limited” participation. It was concluded that measuring participation restrictions following ABI and accounting for both the perspectives of patients and parents is important in outpatient rehabilitation treatment. Furthermore, categorizing the CASP scores appears to be useful in clinical practice.

Chapter 5 focused on the impact of ABI in a child on families at the time of referral to rehabilitation and factors associated with that impact. Parents of patients participating in the same cohort study as described previously completed the PedsQL™ FIM to assess family impact (scores 0-100, with lower scores indicating a higher family impact). For this cross-sectional analysis parent-reported data at baseline were used. Univariate and multivariate regression analyses were conducted to explore the factors associated with family impact. Parents reported substantial family impact (median total score 71.9, IQR 60-85), particularly in the “worrying” domain (65.0, IQR 50-80). Factors associated with higher family impact included the presence of nTBI, referral to rehabilitation longer than six months after ABI onset, worse mental/emotional health, worse HRQoL of the entire family, and the presence of premorbid learning/behavioral/health-related problems. Higher age and TBI severity did not seem to have a significant effect on family impact. These results emphasize the necessity of measuring the impact on families within the population of young patients with ABI.

In **Chapter 6**, the course of family impact over time and its relationship with patients’ HRQoL was investigated This longitudinal study used the PedsQL™ FIM and the parent-reported PedsQL™ GCS-4.0 (to assess patients’ HRQoL) at the time of referral and one and two years later. The group of patients were split into TBI and nTBI groups. Linear mixed models were used to examine family impact and HRQoL over time (change scores (95% CI), p-values). Repeated measure correlations were used to find correlations between family impact and patients’ HRQoL (r_{rm}, p-values). Baseline data from 181 parents of patients with TBI and 65 with nTBI were used for this analysis. The results showed that family impact did not change over time in the TBI group (+2.1, (-1.9, 6.2), $p > 0.05$) and was still considerable after two years (mean score 77.0). Only worrying improved significantly in the TBI group (+8.6, (2.1, 15.1), $p < 0.05$). In contrast with TBI, family impact improved statistically significantly in the nTBI group (+5.8, (0.2, 11.4), $p < 0.05$). A statistically significant improvement was also seen for all domains of the patients’ HRQoL over the same period ($p < 0.05$) in both the TBI and nTBI groups. A moderately strong longitudinal correlation between family impact and patients' HRQoL (r_{rm}=0.51, $p < 0.001$) was observed. These results indicate that apart from HRQoL, family impact should be monitored before, during, and after rehabilitation in young patients with ABI.

Section 2. Joint collaborations between rehabilitation centers to optimize care for young individuals with ABI

Next to describing persistent consequences of ABI, the provision of appropriate care to address these consequences is very important. For this purpose, it is important to gain insight into the current delivery of rehabilitative care, which can be described in terms of its structure, and outcomes.[20] Regarding the studies in **Chapters 7 and 8**, fourteen Dutch rehabilitation centers (out of sixteen in total) that provide medical specialist rehabilitation for young individuals with ABI participated in project "Participate?! Next Step". Each rehabilitation center proposed one (or two) lead experts who assisted throughout the project on behalf of their rehabilitation center. Regarding the structure of rehabilitation for this population, similarities and differences across rehabilitation centers were identified in **Chapter 7**. With respect to the outcomes and content of treatment, the consensus-building process of a national treatment framework is described in **Chapter 8**.

Chapter 7 comprises a cross-sectional survey study, where rehabilitation professionals completed a 21-item questionnaire on the structure of outpatient ABI rehabilitation. The topics were related to the admission/discharge criteria, organization of rehabilitation, and aftercare. The similarity in rehabilitation practice was defined as ≥ 75% concordance of responses among rehabilitation centers. Twelve rehabilitation centers participated. All rehabilitation centers reported the use of admission and discharge criteria, however their content varied. Differences were also observed in the presence of 'transition teams' for young adults (present in four out of twelve rehabilitation centers (33%)) and general ABI-treatment programs in terms of the organization of rehabilitation (present in eight out of twelve rehabilitation centers (67%)) stated they used such a program. For aftercare, differences were observed in the timing of discharge and follow-up. This study highlighted variations in the delivery of care for patients with ABI across Dutch rehabilitation centers, suggesting the need for the development of a national framework to enhance the provision of comparable care for young individuals with ABI.

The consensus-building process of a national framework for healthcare professionals including preferred assessments, interventions, and PE-materials for young individuals with ABI in the rehabilitation setting is described in **Chapter 8**. This study comprised a three-round Delphi study involving healthcare professionals from 14 Dutch rehabilitation centers with different disciplines (physiatrists, psychologists, social workers, physical therapists, occupational therapists, and speech therapists). In the first two online rounds, currently used assessments, interventions, and psycho educational materials (PE-materials) were collected, stepwise prioritized, and listed per occupation discipline according to ICF domains. Results from the first two rounds were discussed in a live consensus meeting to reach consensus on all three aspects of the framework and its implementation and usability in current practice. A total of 74 healthcare professionals from 14 rehabilitation centers participated in this study. After all Delphi rounds, consensus was reached on the use of 37 preferred assessments, 25 interventions, and 27 preferred PE materials. Additionally, consensus was reached on how to use the framework to enhance the selection of appropriate assessments and interventions in current practice. The developed consensus-based national framework aids in uniforming and optimizing the delivery of care for young individuals with ABI across Dutch rehabilitation centers.

GENERAL DISCUSSION

Identifying, targeting, evaluating and monitoring the consequences of Acquired Brain Injury (ABI) in children, adolescents and young adults (4-25 years old) are essential elements of medical specialist rehabilitation care for this patient group. Currently, there are a number of knowledge gaps regarding the occurrence and severity of consequences and the delivery of rehabilitation care, hindering the optimalization of care. This thesis addressed the specific characteristics of ABI in young individuals and their families who were referred for rehabilitation, examined the consequences of ABI in terms of various aspects of health status (**Section 1**), as well as the current and desired delivery of medical specialist rehabilitation for this patient population (**Section 2**).

This General discussion reflects on this thesis in the context of the available knowledge from existing literature, highlights methodological considerations, provides insights into potential areas for future research, and discusses implications for rehabilitation practice.

Section 1. Persisting consequences of ABI in young individuals and families referred to outpatient rehabilitation in the Netherlands

The studies in **Chapters 2 to 6** of his thesis showed that the majority of young individuals who were referred to a rehabilitation center due to persisting ABI-related consequences had mild injuries. Nevertheless, it was found that the whole population described in this thesis experienced severe and long-lasting consequences from their ABI on multiple domains of the World Health Organization International Classification of Functioning, Disability and Health (ICF).[21]

Impairments in body functions and structures: Fatigue in young patients with ABI

Two studies in this thesis found that young patients with ABI referred for outpatient rehabilitation treatment had problems on the level of the ICF domain Body functions and structures (**Chapters 2 and 3**). In this domain, fatigue was reported to be a severe problem in more than half of the population at referral to rehabilitation (prevalence depending on age, i.e., higher age, more problems). Two years after referral, fatigue remained a prominent problem for most patients. Individuals with higher fatigue levels consequently reported a lower Health Related Quality of Life (HRQoL). Furthermore, in these young individuals, more participation restrictions were seen on the level of the ICF domain Activities and Participation. These findings are consistent with previous studies conducted in young patients with severe neurological disorders, including TBI.[22,23] Not unexpectedly, the patients in our studies had higher fatigue levels compared to hospital-based cohorts of young patients with ABI.[7,24-26] These findings suggest that persistent fatigue may be one of the reasons for admission to medical specialist rehabilitation and underscore the need to consider this group to be a specific subgroup within the general ABI population.

The findings in this thesis emphasized the importance of measuring fatigue in young patients with ABI in the rehabilitation setting. In this thesis, the Pediatric Quality of Life Inventory™ Multidimensional Fatigue Scale (PedsQL™ MFS) was used as measurement instrument for fatigue.[14-16] This patient/parent-reported outcome measure (PROM) comprehensively evaluates fatigue on various domains, including general fatigue, sleep/rest fatigue and cognitive fatigue. It is specifically designed for use in children, adolescents, and young adults with various conditions,[14-16] and reference data is available from Dutch healthy individuals.[14,15] There are other PROMs available to measure fatigue, such as the Fatigue Scale-Child,[27] Patient-Reported Outcomes Measurement Information System (PROMIS)-Pediatric Fatigue,[28] Multidimensional Fatigue Inventory,[29] and Fatigue Impact Scale,[30] however these may be less suitable in the pediatric rehabilitation setting. The reasons for these instruments to be less appropriate are that they either do not cover all fatigue domains[28,30] or only cover a limited age range,[27-30] or are too diagnosis specific for the heterogeneous character of ABI.[27,29] Moreover, for some instruments no reference data are available to compare scores with those of healthy peers.[27-30] PedsQL™ MFS domain scores are each expressed on a 0-100 scale, where lower scores indicate more fatigue. However, the interpretation of these scores in order to make clinical decisions is difficult. To enhance the understanding of PedsQL™ MFS scores, we proposed a fatigue severity categorization system, based on reference data from healthy, age-matched peers,[14,15] which can be used next to the conventional 0-100 score range. This proposed categorization system allows for a quick comparison of fatigue outcomes in relation to healthy individuals. While this system seemed promising, further research into its applicability in clinical practice is required. Apart from interpreting the scores at admission in order to set treatment goals and assign and execute interventions, the interpretation of changes of the scores over time is also important. For that purpose, the Minimally Clinically Important Differences (MCIDs)[31] of the various domains of the PedsQL™ MFS should be established in this population, preferably by using the patient perspective on perceived changes in health status. By using the proposed categorization system, either or not refined based on future studies, and established MCIDs, clinicians and researchers in rehabilitation are enabled to better measure fatigue and evaluate its changes over time.

As is mentioned above, in addition to measuring fatigue it is essential to initiate proven effective treatment interventions to support young patients with ABI with coping with, or reducing fatigue. However, the effectiveness of such treatments has not yet been described in the literature for young individuals with ABI. Furthermore, the studies in this thesis did not evaluate specific fatigue-related treatment in children and youth with ABI either. Nonetheless, effective treatment interventions for fatigue have been evaluated in other populations, such as adolescents and young adults with chronic fatigue syndrome,[32-37] and chronic pain.[38,39] These interventions typically involve either cognitive behavioral therapy (CBT) to improve coping with fatigue in daily life or graded activity training (GAT) to enhance physical fitness.[32-39] For ABI in adults specifically, a study in patients with stroke demonstrated the effectiveness of combining CBT and GAT to improve both coping with fatigue and physical fitness.[40] In future research, it would be of added value to explore the feasibility and the (cost) effectiveness of these interventions in young individuals with ABI in the rehabilitation setting.

Restrictions in participation

A large proportion of young individuals with ABI described in this thesis were found to have daily life problems on the ICF level 'Activities and Participation' as measured with the Child and Adolescent Scale for Participation (CASP) (**Chapters 4 and 6**). Persistent participation restrictions were reported at time of referral to rehabilitation. One and two years thereafter, participation restrictions decreased, but remained prevalent in almost all patients. Participation restrictions were found across various domains, including at home, in school/at work, and in society. Moreover, a clear association with the severity of fatigue was found. It was also seen that parents tended to report less participation restrictions of their children than the children themselves. Participation restrictions have previously been described across various pediatric ABI populations, including patients with severe TBI, other neurological conditions and pediatric oncology.[5,41-46] Our rehabilitation-based cohort showed more severe participation restrictions compared to young patients with ABI seen only in a Dutch hospital.[2]

In the studies in this thesis we used the CASP, which is an often-used PROM that measures participation restrictions in children and adolescents with disabilities, including ABI.[17,18,47] Over the last decade, other assessments for measuring participation have been developed, such as the Children Participation Questionnaire, and the Questionnaire of Young People's Participation.[48,49] However, according to two relatively recent systematic reviews on investigating PROMs that measure participation, the CASP was considered the most suitable PROM to assess participation restrictions on multiple domains in ABI to date, despite its known ceiling effect.[50,51] However, when looking at the population of young individuals with ABI specifically, no normative data for comparison is available, and MCIDs are lacking. To enhance both the scientific and clinical relevance of this instrument, addressing these knowledge gaps for the rehabilitation setting is recommended.

Reducing participation restrictions is one of the most important goals in rehabilitation treatment.[52-55] For the provision of appropriate care for young people with ABI, it is essential to consider environmental factors, such as social environment, as highlighted in the existing literature.[56,57] Currently, several interventions specifically addressing participation restrictions in young individuals are available, such as Social Participation and Navigation (SPAN) developed by Bedell et.al.[58,59] and the Pathways and Resources for Engagement and Participation (PREP) by Anaby et.al.[60,61] SPAN is an app-based intervention aimed at improving social participation,[58,59] and PREP focuses on identifying and implementing strategies to remove environmental barriers that may hinder participation.[60,61] Both interventions were proven effective in children and adolescents with physical disabilities, including those with ABI.[56,57,61,62] Despite their relevance and potential, there are no Dutch versions of either SPAN or PREP. It could therefore be considered to cross-culturally translate and adapt the SPAN and PREP interventions, and evaluate them in the Dutch rehabilitation setting.

Environmental factors: Impact on the family

Impact of ABI on the family concerns the domain of environmental factors of the ICF framework, and is an important aspect to consider in rehabilitation (**Chapters 5 and 6**). In the cohort described in these Chapters, a considerable proportion of the parents reported a severe impact on their families. The observed family impact in our study was notably higher than in a hospital based pediatric ABI cohort,[63] and remained present over time in most families. Regarding factors associated with family impact, a lower HRQoL of the affected child was significantly associated with higher family impact. Our findings are in line with previous research demonstrating a considerable impact of ABI on families as well.[63-67]

In the studies described in **Chapters 5 and 6**, the PedsQL™ Family Impact Module (PedsQL™ FIM) was used. It has been demonstrated previously that this instrument provides valuable insights into the complex parent-reported family impact in the pediatric ABI population.[19] Multiple studies have used this PROM,[65-67] including a Dutch study in a hospital based pediatric ABI cohort,[63] and found the PedsQL™ FIM to be able to adequately detect family impact.[63,65-67] Other studies in pediatric ABI patients investigating family impact have predominantly used qualitative interviews.[68-71] However, despite the valuable insights derived from such studies, in clinical practice it can be challenging for clinicians to quickly interpret the impact on families. The use of a quantitative instrument such as the PedsQL™ FIM enables researchers to compare family impact across study populations, both with ABI and with other conditions. Furthermore, it also enables rehabilitation, physiatrists, psychologists and social workers to make a fast and adequate assessment of family functioning.[19] This can facilitate the detection of family impact and possibly timing of the initiation of interventions throughout all stages of the rehabilitation process. However, to date, no reference data for the PedsQL™ FIM is available to interpret severity compared to the healthy population, and no MCIDs are available to adequately interpret change over time. This hampers clinical decision making, and it is recommended to enhance the clinical relevance of the PedsQL™ FIM in pediatric ABI rehabilitation by addressing these knowledge gaps through future research.

Beyond measuring and monitoring family impact it is important to actively address this impact in rehabilitation practice. Research has demonstrated that involving the family as active participants in the child's rehabilitation process using holistic approaches can lead to improved recovery outcomes.[5,72-77] Specific studies found that family impact can be effectively addressed in various pediatric conditions in Dutch rehabilitation settings, such as physical disabilities and cerebral palsy using family centered interventions.[78,79] However, these interventions were not specifically developed for the pediatric ABI population. Such interventions may also be of added value in the Dutch pediatric ABI rehabilitation context, however their (cost) effectiveness and feasibility must first be established in this specific population.

Transitional stages

In the studies in this thesis, the group of adolescents (aged 13-17 years) and young adults (18-24 years) with ABI reported more severe ABI-related problems in terms of HRQoL, fatigue, and participation compared to children (4-12 years). These problems could potentially have an impact on healthy development on all ICF domains in older patients.[80-82] Therefore, it is crucial to acknowledge the significance of transitional stages where young individuals transition from childhood to adolescence and from adolescence to adulthood,[5,7,81,83,84] in the delivery of age-appropriate rehabilitation care and in research.

Using patient/parent-reported outcome measures in project “Participate?!”: Lessons learned

To our knowledge, no other (inter)national projects, besides project “Participate?!” have measured ABI-related consequences in terms of HRQoL, fatigue, participation, and family impact on such a large scale in rehabilitation cohorts of young individuals with ABI and their parents over time. To measure these consequences across multiple domains of functioning, the PedsQL™ Generic Core Scales-4.0 (GCS-4.0),[11-13] the PedsQL™ MFS,[14-16] the CASP,[17,18] and the PedsQL™ FIM[19] were used which are the most valid, reliable, and widely accepted PROMs to date. These PROMs provided valuable insights into the less visible consequences of ABI in young individuals and their families in the rehabilitation setting (**Section 1** of this thesis) and aided in optimizing care across rehabilitation centers for this population.

To strengthen the applicability of the PROMs used in project “Participate?!” for clinical practice, MCIDs should be established, preferably by using the patient perspective on perceived changes in health status. Furthermore, they should be used in conjunction with objective tools such as physical activity and cognitive assessments to improve goal setting and enable informed decisions on interventions.

A downside of the use of PROMs in project “Participate?!” were the high dropout rates (**Chapters 3 and 6**). At time of referral to rehabilitation, the completion of PROMs was part of routine care opposed to one to two years after referral where participants were asked to complete the PROMs again for research purposes. At that time, participants may have passed the most challenging phase of their recovery, which could have diminished their motivation to invest time and energy in filling out questionnaires. Research has shown that PROMs can be time-consuming which could be experienced as burdensome and difficult for some patients, and lengthy questionnaires can cause higher dropout rates.[85-87] To address dropout rates in follow-up projects, various strategies can be investigated.

First, a two-stage approach could be considered where in stage one a generic questionnaire that screens all relevant ICF domains is used, whereafter in stage two specific PROMs may be used based on relevant outcomes in stage one. For this, pre-defined scores indicating the need for further detailed and personalized examination of daily life consequences after ABI could be used. This approach aligns with value-based healthcare (VBHC) principles, which prioritize high-value care by considering patient/parent-reported outcomes.[88,89] This new approach should be studied in future research, which could lead to a reduction of the burden for both patients and parents and clinicians. Second, PROMs should be seamlessly integrated into the healthcare process, with participants gaining immediate access to their results. Follow-up assessments should occur at the end of rehabilitation treatment instead of one or two years after referral to immediately provide patients and their parents with insights into their treatment progress and goal attainment. Finally, healthcare professionals should be made more aware of the benefits and usability of PROMs in clinical practice. They should actively encourage patients and their parents to complete follow-up PROMs to be able to effectively evaluate treatment.

Section 2. Joint collaborations between rehabilitation centers to optimize care for young individuals with ABI

Over the past few years, a Dutch consortium of healthcare professionals called 'Brain injury and Youth' (in Dutch: Hersenletsel en Jeugd; HeJ) has facilitated collaborative efforts from rehabilitation centers and network partners to enhance the treatment of and support for young individuals with ABI and their families. In the studies described in **Chapters 7 and 8** of this thesis, the network partners contributed to the investigation of practice variation between rehabilitation centers and the creation of a national consensus-based framework for rehabilitation treatment for young individuals with ABI and their families (project "Participate Next Step").

Differences and similarities in Dutch rehabilitation care

In **Chapter 7** of this thesis, practice variation (differences and similarities) regarding the structure of rehabilitation care for young individuals with ABI and their families in the Netherlands was studied. Despite the identification of similarities, differences were found in terms of admission and discharge criteria, treatment content and aftercare, which was in line with previous research in stroke and arthritis rehabilitation.[10,90,91] The occurrence of practice variation is relevant, as indeed the recognition and reduction of differences in health delivery were found to be significant steps towards the optimization of care delivery across healthcare practices.[92-94] In that light, our findings may feed the discussion among rehabilitation professionals from different rehabilitation centers on structural aspects of care delivery, such as specific admission/discharge criteria, treatment content and dosage and the provision of aftercare. Due to the national nature of our study, findings are limited regarding their generalizability to other countries. However, the research design and method used could serve as a blueprint for studies on an international scale, allowing for broader perspectives and comparisons.

Creating a national consensus-based treatment framework

Chapter 8 of this thesis outlined the development of a national consensus-based treatment framework, using a Delphi method.[95-97] This development was initiated based on the clinical observation that healthcare professionals in rehabilitation used a broad range of assessments, interventions, and psycho educational materials, in the absence of guidelines or other forms of consensus statements on the delivery of specialist rehabilitation care for young individuals with ABI. In other areas, including arthritis, adult ABI and pediatric cerebral palsy rehabilitation, frameworks for the assessments and/or interventions that are important during treatment of these specific populations are available.[98-101] Such a framework did not exist for young individuals with ABI and through the Delphi study described in **Chapter 8**, this was addressed. Consensus was reached on what assessments, interventions and psychoeducational materials were most suitable to use in the rehabilitation of young individuals with ABI. Healthcare professionals can use this framework as a resource to make tailored choices based on the ICF domains in terms of assessments, goal setting, assignment of treatments, and treatment evaluation to create a personalized program.[102,103]

With respect to the framework that eventually resulted from the study in **Chapter 8**, it must be noted that not all assessments, interventions and psychoeducational materials that were agreed upon in the framework were specifically developed for the population of young individuals with ABI. Despite the fact that many assessments and interventions included in the framework are generic and are used in other pediatric rehabilitation populations they may be suitable to be used in young individuals with ABI as well. However, it is worth exploring if they fully meet the needs and wishes of this specific population in order to further optimize care. Moreover, future research should involve the exploration of the usability and the content of the framework in rehabilitation practice. Gaps in knowledge on cut-off points and/or MCIDs of assessments should be addressed to enhance the usability of these specific outcome assessments in evaluating treatment in clinical practice. Furthermore, usability of interventions, and psycho educational materials in current rehabilitation practice should be investigated as well. This enables a transition from practice based to evidence based treatment for the target group.

Project “Participate Next Step”: lessons learned and steps to be taken

The primary goal of project “Participate Next Step” was to optimize rehabilitation care for young individuals with ABI and their families. In this project cooperative efforts across rehabilitation centers led to valuable insights on similarities and differences across centers and the creation of a national framework for the provision of rehabilitation care in this specific patient group. Joint collaborations between healthcare facilities are essential to optimize care for specific populations. “Participate Next Step” project strengthened the collaborative network within and beyond the Brain injury and Youth (HeJ) consortium, involving 14 out of 16 centers, delivering rehabilitation care for young individuals with ABI across the Netherlands. Additionally, lead experts (1 to 2 per center) from the 14 participating centers played a crucial role as connectors within their own center and between participating centers. They delivered valuable assistance throughout the project by describing the structural aspects of rehabilitation processes and providing their expert perspective on the rehabilitation of this specific population and the future implementation of the national framework.

Experiences in this project can be used as an example for other commonly seen health conditions in outpatient rehabilitation care. However, several limitations for this project must be noted as well. First, only 14 out of 16 rehabilitation centers that provide outpatient rehabilitation care for young individuals with ABI participated. Additionally, we relied on healthcare professionals' perspectives only, which may not represent all viewpoints on the optimization of care among young individuals with ABI. Second, even though a user group comprising young individuals with ABI and parents of children with ABI was involved in the project "Participate Next Step", they did not actively participate in the Delphi study. Therefore, their perspectives on what they consider important during rehabilitation were not included. Future research should proactively engage all stakeholders when conducting studies, also including healthcare professionals, management professionals and young individuals with ABI and their families, aligning with literature recommendations,[104-106] and principles of VBHC.[88,89] For instance, patient involvement and engagement should be considered in research which could be addressed by including patients as active participants in research groups[107,108] to comprehensively understand their needs and preferences in further optimizing rehabilitation for this population.

Directions for future research and implications for clinical practice

With the knowledge and insights acquired from this thesis, we are on the road to optimize rehabilitation care for young individuals with ABI and their families. Along this journey suggested directions for future research are as follows:

- Continuous research on measuring and monitoring ABI-related consequences such as diminished HRQoL, fatigue, restricted participation, and family impact in young individuals and their families.
- Development of, and research into the effectiveness and cost effectiveness, of specific interventions to reduce fatigue, participation restrictions and family impact.
- Establishing MCIDs for the PedsQL™ GCS-4.0, the PedsQL™ MFS, the CASP, and the PedsQL™ FIM PROMs to quantify clinically meaningful progress.
- Evaluating the content of the developed framework by conducting both qualitative and quantitative evaluations with input from healthcare professionals and the target group in order to create a more well-founded and concise framework.
- Extend the participation of young individuals with ABI and their families in future research and further incorporating their (unmet) needs and wishes.

For rehabilitation practice in the Netherlands, the following implications could be considered:

- The studies in this thesis and clinical practice suggest that the systematic use of PROM outcomes not only for goal setting, but also to monitor and evaluate treatment throughout the whole rehabilitation process should be optimized. A proper evaluation will facilitate the transition to, for example, primary care.
- Differences in admission/discharge criteria, and aftercare across rehabilitation centers should be further analyzed and consensus should be reached on which criteria to use and how aftercare should be provided.
- Age-appropriate rehabilitation transition care and follow-up should be further integrated into rehabilitation care.
- Joint collaborations between rehabilitation centers should be continued and strengthening collaborative networks across, hospitals, and primary care providers should be considered. For this, lead experts should serve as valuable connectors.

This thesis emphasizes the importance of a holistic approach to rehabilitation and lays the foundation for future initiatives aiming to further optimize the right rehabilitation treatment at the right time, at the right place for young individuals with ABI and their families.

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