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

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CHAPTER 8

A national consensus-based framework on preferred assessments and interventions in current treatment for young people with acquired brain injury in Dutch rehabilitation centers

Submitted

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ABSTRACT

Purpose

To create a consensus-based framework with preferred assessments, interventions, and psychoeducational materials (PE-materials) to be used in pediatric ABI-rehabilitation to optimize the delivery of comparable care.

Methods

For this three-round Delphi study, healthcare professionals (physiatrists, psychologists, social workers, physical/occupational/speech/language therapists) from RCs providing care for young people with ABI were invited to participate. In the first two (online) rounds, currently used assessments/interventions/PE-materials were collected, stepwise-prioritized, subsequently listed per discipline, and classified per International-Classification-of-Functioning (ICF)-domain. Results from rounds one/two were discussed in a consensus meeting (in person), aiming to reach agreements on assessments/interventions/PE-materials in the national framework and how to use this in current practice.

Results

Seventy-four healthcare professionals from 14 rehabilitation centers (RCs) participated. After Delphi round one, 163 assessments, 39 interventions, and 64 PE-materials were collected. After round two, the selection was narrowed down to n=51/n=34/n=28, respectively. After round three, consensus was reached on 37 assessments, 25 interventions (divided over all disciplines/classified per ICF-domain), 27 PE-materials, as well as consensus on the use of the framework by all participating RC to enhance clinical reasoning in current practice.

Conclusions

A consensus-based national framework in ABI rehabilitation has been developed which is now available to optimize the delivery of care for young people with ABI across Dutch RCs.

Keywords: Health Care Organizations and Systems, Pediatrics, Clinical Practice Patterns/Guidelines/Resource Use/ Evidence Based Practice

INTRODUCTION

Acquired brain injury (ABI) is a comprehensive term for brain damage that occurs after birth including traumatic brain injury (TBI) and non-traumatic brain injury (nTBI).[1] ABI is prevalent in young people under the age of 25.[2,3] ABI can lead to significant disruptions in the development of a young person and it is known to be a leading cause of disability in this age group, worldwide,[2,3] as well as in the Netherlands.[4] Young people with ABI constitute a heterogeneous population in terms of age, type of injury, injury severity, and impairment levels, as well as in perceived limitations in activities and restrictions in participation.[5-7] For persisting problems in daily life young patients may at some point require rehabilitation treatment in specialized multidisciplinary rehabilitation teams.[8-11]

Several studies on the effectiveness of rehabilitation treatment for individuals with disabilities, including young patients with ABI, reported that the ultimate goal of rehabilitation treatment is optimal participation in society. The actual focus and content of rehabilitation treatment appeared to vary across these studies despite similarities in populations.[8,9,12-14] Variability in the provision of rehabilitation treatment for young patients with ABI is not only observed in the literature,[8,9,12-14] but also in daily practice. Despite the existence of a Dutch standard for quality of care for children (0-18 years) with TBI in The Netherlands,[15] exact structures or rehabilitation content is lacking. Therefore, substantial room for variation in rehabilitation treatment across rehabilitation centers (RCs) is possible.[15] Assessments (e.g., physical and cognitive) are considered particularly important in rehabilitation treatment and are widely used to determine the patient's current functioning, goalsetting,[16-18] and to evaluate interventions.[16,17] It is likely that the variation in assessments and interventions may in part be related to the scarcity of practice guidelines or recommendations on the rehabilitation treatment of young patients with ABI. Practice variations described in the literature and observed in daily practice may be signalizing suboptimal care, as was described in previous studies on rehabilitation treatment in adult populations (stroke/arthritis rehabilitation).[19,20]

The literature regarding the content of rehabilitation treatment for children and adolescents with ABI is scarce. Several studies give an overview of assessments and interventions for rehabilitation populations.[13,21-25] These studies focused on specific populations i.e., adults with stroke and ABI,[21] children with stroke,[22] and children with ABI in the acute phase.[23] However, these studies did not focus on multidisciplinary rehabilitation treatment for the population of young patients (4-25 years) with ABI as a whole.[13,23-25] Furthermore, psychoeducation (PE) is considered an important element of treatment interventions in pediatric ABI rehabilitation and many materials are available.[10,26] However, a list specific for the population of young patients with ABI in the rehabilitation setting is lacking to date.

Rehabilitation professionals (e.g., physiatrists, psychologists, physical therapists, occupational therapists, speech/language therapists, and social workers) in the Netherlands show a growing interest in harmonizing assessments and interventions used in pediatric rehabilitation treatment. Creating structured rehabilitation frameworks describing assessments and interventions are also in line with the principles of value-based healthcare (VBHC) to provide the best possible care for each individual child and their family.[27]

A national framework containing assessments, interventions, and psychoeducational materials (PE-materials) could decrease undesired practice variation and enhance the offering of comparable care for young patients with ABI regardless of where they live in the Netherlands. Further, it could stimulate collaborations and joint research projects across RCs in terms of (cost)-effectiveness and efficacy, which is also in line with the principles of VBHC.[27] Therefore, the goal of the current study was to create a national consensus-based framework on preferred assessments, interventions and PE in current outpatient rehabilitation treatment for young people, aged 4 to 25 years, with acquired brain injury in Dutch RCs.

METHODS

Design

In the current study, a three-round Delphi method was used to collect assessments and interventions used in rehabilitation treatment for children with ABI and to reach consensus among physiatrists and healthcare professionals across RCs regarding these assessments and interventions. In this study, the guidelines for the Delphi Survey Technique by Hasson et.al. were used.[28] In line with these guidelines,[28] two Delphi rounds addressed preferred assessments and interventions using online questionnaires (e-Delphi method [29]), followed by a consensus meeting using a nominal group technique (group-brainstorming through writing down, sharing, and voting on topics).[30] A list of PE-materials used in current practice was also collected during the Delphi rounds.

Setting

The current study was part of the multicenter project “Participate?! Next Step” (2021-2023) in which 14 Dutch RCs providing rehabilitation treatment for young patients between 4-25 years old with ABI participated. The project was led by a project group that consisted of a PhD candidate FA), and four senior researchers (AdK, FvM, TVV, and MvdH), all of whom are authors of the current study. The project also had an advisory board consisting of physiatrists, psychologists, and senior researchers (n=8). Their task was to advise and

assist in designing and conceptualizing the project as well as the outlines of the current Delphi study. Six members of the advisory board have contributed as authors in the current study (IR, SL, KH, PdK, StW, and CR). The project and study protocol were reviewed and approved by the medical ethical review board of the Leiden University Medical Center (P15.165-addendum-1). The local research committees from all participating RCs approved the project, including the current study.

Recruitment of participants

The physiatrists and healthcare professionals that were involved in the project "Participate?! Next Step" within the participating RCs were asked to propose up to 12 of their colleagues (physiatrists/healthcare professionals, up to two per discipline) to participate in the Delphi study. Potential participants were eligible to participate when they were (1) a physiatrist or a healthcare professional from one of the following disciplines: psychology, physical therapy (PT), occupational therapy (OT), speech/language therapy (SLT), or social work (SW); (2) when they were working with children and/or adolescents and/or young adults (4-25 years old) with ABI in daily practice; and (3) when they were willing to participate in all three rounds of the Delphi study. Subsequently, the project group provided information regarding the procedure, and planning of the Delphi study to potential participants by e-mail.

First Delphi round: In the first round of the Delphi study, participants received a unique link (by e-mail) to access an online questionnaire containing five questions. The first two questions were general, i.e., the RC of employment, discipline, and years of experience working with young patients with ABI (< 5 / ≥ 5 years). The other three questions were discipline-specific questions, concerning which assessments, interventions, and PE-materials they use within their discipline in current practice. Participants were asked to provide any information available on the description and/or validity of the assessments, interventions, and PE-materials. The participating physiatrists monitored and complimented the assessments, interventions, and PE-materials that were proposed by the healthcare professionals in their own RCs. The project group combined data from all completed questionnaires. The assessments, interventions, and PE-materials in daily practice across RCs in the first round were filtered for repeated listings. The surveys were conducted using Castor EDC. In line with the current Dutch standard of practice-based care,[15] assessments and interventions used in two or more of the participating RCs were included in the list for the second round. Thereafter, they were categorized by discipline (where applicable) and classified by the International Classification of Functioning (ICF) domains (body functions (b), activities and participation (d), environmental factors (e), and body structures (s)),[31] through ICF linking rules.[32] All described PE-materials were included in the list and proposed for the second Delphi round.

Second Delphi round: The participants who filled out the questionnaire in the first round were asked to participate in the second round. For every assessment and intervention that was selected after analyzing the first round, participants were asked whether they thought it should be included in the national framework on current practice (yes/no). After collecting the results of the second round, the project group used a level of agreement to reach consensus.

- When ≥ 75% of the respondents answered 'yes' to a proposed assessment/intervention the item was included in the concept framework.
- If 75% or more (≥) of the answers per assessment/intervention were answered by 'no' the assessment/intervention was rejected.
- If 25-75% of the answers per item were answered by 'yes', the assessment/intervention was put on a list to be discussed in the third Delphi round.

The concept framework for the discussion in the third round contained the items that were selected after the second round (assessments/interventions with ≥ 75% 'yes') and the items that had to be discussed were highlighted (items with 25-75% 'yes'). During the second round participants were asked to check the completeness/appropriateness of the PE-materials.

Third Delphi round: The third Delphi round consisted of an in-person meeting of approximately 4 hours to discuss and reach consensus on the results of the first two rounds. Prior to the meeting (approximately two weeks), all participants from the RCs received the concept framework in preparation for the meeting. One rehabilitation physiatrist and one other healthcare professional (either a psychologist, PT, OT, SLT, or SW) from each RC were allowed to be present due to national restrictions during the COVID-19 pandemic at the time. They were asked to represent their RC as a whole. The project group was present as well. The meeting was divided into two parts.

In the first part of the meeting, the way in which the national framework should be used for individual patients with ABI and their families in rehabilitation treatment was discussed. The aim of the discussion was to reach consensus regarding the best suitable and discipline-specific techniques for selecting assessments and interventions in clinical practice within the national framework for an individual patient with ABI.

In the second part of the consensus meeting, the 'concept framework' was discussed. Participants voted for acceptance/rejection per assessment/intervention that was listed in the category '25-75% yes'. Again, ≥ 75% agreement among RCs that were represented by physiatrists and healthcare professionals was used to include assessment/intervention. Less than 75% agreement between RCs meant no consensus was reached and therefore,

the assessment/intervention would not be included in the national framework. Thereafter, the list with assessments and interventions that were already accepted in the second Delphi round (i.e., with more than 75% answering 'yes') were presented and the participants had the opportunity to discuss these items prior to 'final acceptance'.

The list of PE-materials was proposed as well, for a final check of completeness. After the consensus meeting, the project group made a final list of assessments and interventions per discipline, and PE-materials (generic) that reached consensus in the Delphi process.

Analyses

All analyses were done using SPSS (IBM SPSS Statistics for Mac, version 28, Armonk, NY: IBM Corp). Descriptive statistics were used for the characteristics of the participants. Descriptive statistics were used to present responses from the first round and were expressed as numbers (n) and percentages (%). The dichotomous (yes/no) answers in the second round and the final accepted items in the third round are presented as numbers and frequencies, as well.

RESULTS

From 14 RCs in the Netherlands, 84 healthcare professionals were invited to participate. Of those, 76 (90%) responded stating that they were willing to participate in the study and completed the first round. The flow of included participants in this study is presented in Figure 1. Table 1 shows the characteristics of the participants. Eleven physiatrists (14.5%), 15 psychologists (20%), 10 PT (13%), 19 OT (25%), 12 SLT (16%), and 9 SW (11.5%) participated. In the second round, 56 participants responded (74% of 76 responders in total). Finally, 28 physiatrists and/or healthcare professionals that represented their RC and the project group (n=5) participated in the in-person consensus meeting for the third round (total participants 33).

First and second online Delphi rounds

After the first Delphi round, a total of 136 unique assessments were listed. During the first Delphi round, the psychologists, representing all participating RCs, proposed a battery for neuropsychological testing, which was listed throughout the Delphi rounds as one assessment. Fifty-one assessments were considered to be related to the field of PT, 45 for OT, 38 for SLT, and two for SW (Table 2). Concerning the interventions, 39 were listed after the first round; 9 for psychology, 8 for PT, 13 for OT, 6 for SLT and 5 for SW (Table 3). Twenty-seven PE-materials were collected and included in the list (Table 4).

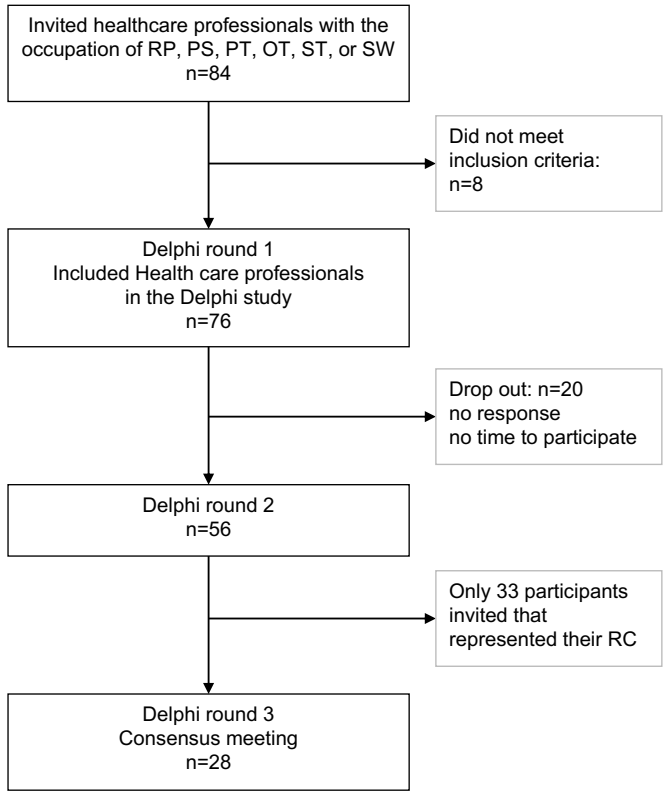

Figure 1. Flow diagram of participants in the Delphi study on assessments, interventions, and psychoeducation materials used in outpatient rehabilitation treatment of young patients with ABI.
RP: Rehabilitation physiatrists, PS: Psychologists, PT: Physical Therapists, OT: Occupational Therapists, ST: Speech Therapists, SW: Social Workers.

For the second Delphi round, the number of assessments narrowed down from 136 to 45 and interventions from 39 to 34, PE-materials remained at 27.

Consensus meeting (third Delphi round)

In the first part of the meeting, consensus was reached on the underlining importance of working in a multidisciplinary and interdisciplinary team due to the heterogeneity and complexity of the target group where the expertise of each discipline complements the other. For example, physical therapists and occupational therapists could combine their expertise when using an intervention to enhance the best possible care for an individual. Consensus was also reached on how to select appropriate assessments and interventions from the framework to use with the individual patient. A majority of participants (> 75%)

Table 1. Characteristics of participating health care professionals in the three-round Delphi study.

Characteristics of participants n=76	Number (%)
Rehabilitation center, n (%)	
· Adelante, Valkenburg	4 (5%)
· Basalt, The Hague	9 (11.5%)
· de Hoogstraat, Utrecht	5 (7%)
· Heliomare, Wijk aan Zee	4 (5%)
· Klimmendaal, Apeldoorn	8 (10%)
· Libra, Eindhoven	4 (5%)
· Merem, Hilversum	5 (7%)
· Reade, Amsterdam	5 (7%)
· Revalidatie Friesland, Beetsterzwaag	8 (10%)
· Revant, Breda	9 (11.5%)
· Roessingh, Enschede	5 (7%)
· Vogellanden, Zwolle	8 (10%)
· Rijndam, Rotterdam	1 (2%)
· UMCG/Beatrixoord	1 (2%)
Discipline, n (%)	
· Physiatrists	11 (14.5%)
· Psychologists	15 (20%)
· Physical therapists	10 (13%)
· Occupational therapists	19 (25%)
· Speech language therapists	12 (16%)
· Social workers	9 (11.5%)
Years of working experience with the target group, n (%)	
· < 5 years	23 (30%)
· > 5 years	53 (70%)

agreed that clinical reasoning was important when selecting assessments and interventions for individual patients. Participants suggested to adjust a previously developed flowchart (Swinkels et.al.) for facilitating the selection of the most appropriate assessments and interventions from the framework to be suitable for the individual patient with ABI. After the consensus meeting the project group developed this flow chart (Figure 2), which participants approved (by email).

During the second part of the meeting, consensus was reached on a list of 37 assessments to be included in the national consensus-based framework across the disciplines: 9 for PT, 10 for OT, 15 for SLT, and 2 for SW. The psychologists present during the meeting confirmed the battery for neuropsychological testing was to be listed as one assessment in the national framework. Furthermore, consensus was reached on a total of 25 interventions: 5 for psychology, 6 for PT, 7 for OT, 4 for SLT, and 3 for SW. The listed assessments and

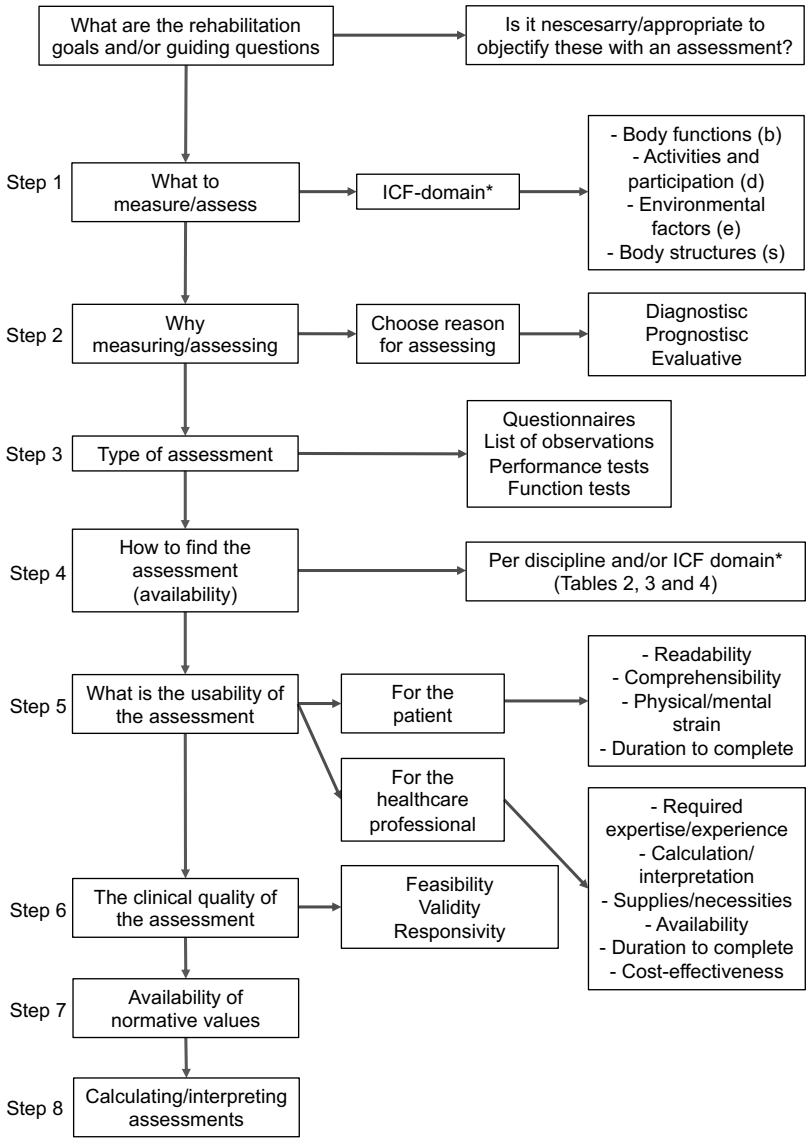

Figure 2. Flowchart for selecting appropriate assessments in clinical practice from the national consensus-based framework.
Based on: "Raamwerk klinimetrie voor evidence-based products", Swinkels et.al. 2016.33
* Body functions (b), activities and participation (d), environmental factors (e), and body structures (s): domains and sub-domains of the International Classification of Functioning, Disability and Health (ICF).

interventions corresponded with all ICF domains including body functions and structures (n=25 assessments, n=15 interventions), activities and participation (n=30 assessments, n=19 interventions), environmental factors (n=8 assessments, n=11 interventions), and body structures (n=20 assessments, n=10 interventions). Finally, all listed PE-materials were confirmed by the group and included in the national framework.

All assessments, interventions, and PE-materials that were confirmed during the consensus meeting were added and merged by the project group to create the national consensus-based framework. Approximately two months after the meeting, the framework was sent to the participating physiatrists and healthcare professionals for a final check. This did not result in any alterations in the list.

See Table 2, Table 3, and Table 4 for the list of all accepted assessments, interventions, and PE-materials in the national consensus-based framework.

Table 2. Assessments per ICF-domain after the three-round Delphi study among healthcare professionals from fourteen Dutch rehabilitation centers.

Discipline	Delphi round 1	Delphi round 2	Result after consensus meeting	
			Accepted assessment	
Psychology	n=1	n=1	n=1	Battery for Neuropsychological testing *
Physical therapy	n=51	n=17	n=91	Two-point discrimination test
				Six-minute walking test (6MWT)
				Standaard lichamelijk onderzoek *
				Gait analysis
				Acquired Brain Injury Challenge Assessment (ABI-CA)
				Visual Analogue Scale (VAS)
				Shuttle run test (SRT)
				Hand-held Dynamometer (HHD)
				Functional Strength Measurement (FSM)
Occupational therapy	n=45	n=10	n=10	"Systematische Opsporing Schrijfproblemen (SOS-2-NL)" writing test *
				Jamar meter / pinch meter
				Nine Hole Peg Test
				AssistingHand Assessment (AHA)
				"Activiteitenweger" *
				Sensory Profile (SP)
				Daily activities observation list ("ADL observatielijst") *
				Canadian Occupational Performance Measure (COPM)
				Perceive, Recall, Plan Perform (PRPP)
				The Beery-Buktenica Developmental Test of Visual-Motor Integration, 6th Edition (Beery VMI 6TH edition)
Speech therapy	n=38	n=15	n=15	"Nederlandstalig Dysartrieonderzoek – Kinderen (NDO-K) *
				Token Test
				Peabody Picture Vocabulary Test
				Clinical Evaluation of Language Fundamentals (CELF-5)
				Schlichting test *
				Computer-Based Instrument for Low Motor Language Testing (C-BiLLT)
				Boston naming Task (BNT) *
				Renfrew Expressive Vocabulary Test (REV-T)
				Analysis of spontaneous language production
				90ml swallow test
				Cervical auscultation *
				The Radboud Dysarthria Assessment
				Sunnybrook
				Drooling quotient
				Diagnostic instrument for apraxia (DIAS) *
Social work	n=2	n=2	n=2	Family Questionnaire *
				Questionnaire focused on burden of care *
TOTAL	n=136	n=45	n=37	

* Outcome measure only available and/or only developed in Dutch. # body functions (b), activities and participation (d), environmental factors (e), and body structures (s): domains and sub-domains of the International Classification of Functioning, Disability and Health (ICF). 1 additional physical therapy assessments (n=6) that can be used as alternatives for the accepted assessments: Medical Research Council (MRC)-scale test, Functionele spierkracht test*, Steep Ramp Test, Bruce test, Movement-ABC-2 Test, Gross motor function measure (GMFM).

	ICF (sub)domain#			
	b	**d**	**e**	**s**
	b1	d1/d2	e3/e4	s1
	b256/b280			
	b450	d420/d450		s770/s730
	b735	d420		s730/s730
		d420/d450		s770/s730
	b450/b7300	d420/d450		s770/s730
	b280			
	b450/b740	d420/d450		s770/s730
	b7300/b740			
	b450/b7300	d420/d450		s770/s730
	b147/b760	d440		s750
	b7300	d440		s750
	b147/b760	d440		s750
	b147/b760	d440		s750
		d2303		
		d2303/d710-d779	e310-e399	
		d2303/d710-d779	e310-e399	
		d2303/d710-d779	e310-e399	
	b147	d2303/d710-d779	e310-e399	
	b147	d2303		s750
	b167/b310-b330			
	b167/b310-b330			
	b167/b310-b330			
	b167/b310-b330			
	b167/b310-b330	d330		s310-s340
	b167/b310-b330	d330		
	b167/b310-b330	d330		
	b167/b310-b330	d330		
	b167/b310-b330	d330	e310-e399	s310-s340
		d330/d550-d560		s310-s340
		d330/d550-d560		s310-s340
		d330/d550-d560		s310-s340
		d330/d550-d560		s310-s340
		d330/d550-d560		s310-s340
	b167/b310-b330	d330		s310-s340
		d710-d799	e310-e399	
		d710-d799	e310-e399	

Table 3. Interventions per ICF-domain after the three-round Delphi study among healthcare professionals from fourteen Dutch rehabilitation centers.

Discipline	Delphi round 1	Delphi round 2	Result after consensus meeting	
			Accepted intervention	
Psychology	n=9	n=7	n=5	Cognitive behavior Therapy (CBT)
				Eye Movement Desensitization & Reprocessing (EMDR)
				Family meetings
				Acceptance & Commitment Therapy (ACT) [1]
				Strategy training *
Physical therapy	n=8	n=8	n=6	Graded activity / graded exposure [1]
				Fitness training
				Functional training
				Mindfulness
				Training through the "frequency, intensity, time, and type" (FITT)-factors
				Advice regarding sports
Occupational therapy	n=13	n=8	n=7	Strategy training *
				Wheelchair training *
				Graded activity /graded exposure [1]
				Constrained- Induced Movement Therapy (CIMT)
				Independence training *
				Niet Rennen Maar Plannen *
				Errorless learning method
Speech therapy	n=6	n=6	n=4	Prompts Restructuring Oral Muscular Phonetic Targets
				Language therapy*
				Assistive communication training*
				Logo Art Online
Social work	n=5	n=5	n=3	Family meetings
				Acceptance and Commitment Therapy (ACT)[1]
				Therapy focused on the whole social system*
TOTAL	n=39	n=34	n=25	

* Intervention only available and/or only developed in Dutch. # body functions (b), activities and participation (d), environmental factors (e), and body structures (s): domains and sub-domains of the International Classification of Functioning, Disability and Health (ICF). 1Test applicable for multiple disciplines.

	ICF (sub)domain#			
	b	**d**	**e**	**s**
		d250		
		d250		
			e310-e399	
	b1	d160-d179	e310-e399	s110
	b1	d160-d179		s110
	b740		e3/e4	
	b450/b740	d450		s730/s770
	b450/b740	d420/d450		s730/s770
	b735			
	b450/b740/b7300	d420/d450		s730/s770
			e3/e4	
	b1/b147	d160-d179		s110
	b147/b740/b760	d440		s750
	b740		e3/e4	
	b147/b760	d2303/d440/d710-d779	e330-e399	s750
			e330-e399	
		d2303/d440/d710-d779		
		d2303/d440/d710-d779		
	b167/b330	d330	s310-s340	
	b167/b310/b330	d330	s310-s340	
	b167/b310/b330	d330	e330-e399	
	b167/b330	d330		
		d710-d799	e310-e399	
		d710-d799	e310-e399	
		d710-d799	e310-e399	

Table 4. Psychoeducational materials after the three-round Delphi study among healthcare professionals from fourteen Dutch rehabilitation centers.

Result after consensus meeting		
Accepted psychoeducation		
Total number	**Specification of type**	**Name/title**
n=27	Book n=13	"Ik hou nog steeds van appeltaart" *
		"Brainstars" *
		"Speels brein" *
		"Mag ik ook ff" *
		"NAH niet altijd handig" *
		"Waarom heeft een krokodil zo'n platte kop" *
		"Elvin het vergeetachtige olifantje" *
		"Er lijkt niets met ons aan de hand maar dat is niet zo. Ons hoofd moet heel hard werken" *
		"De puzzel van nah" *
		"Bordje vol" *
		"Omgaan met hersenletsel" *
		"De Zorgzame Giraffe, autobiografisch verhaal over Niet Aangeboren Hersenletsel" *
		"Volle Hoofden Boek (werkboek voor kinderen/ jongeren)" *
	Folder n=4	"Hoe verder na traumatisch hersenletsel bij kinderen en jongeren" *
		"Slaaptips voor kinderen en pubers" *
		"Het NAH boekje voor onderwijs" *
		Brains ahead! study
	Internet Site n=7	Breinstraat.nl *
		hersenletseluitleg.nl *
		Kinderneurologie.eu *
		Overprikkeling.com *
		"Afasienet.com" *
		"Brain Blocks"
		"Methode RIK (Revalidatie En Ik)" *
	Movie n=1	"Ze zeggen dat ik zo veranderd ben" *
	Standard of care n=1	Traumatisch Hersenletsel Kinderen & Jongeren *
	Application n=1	Energie/activiteitenweger *

* Psychoeducation only available and/or only developed in Dutch.

DISCUSSION

In the current study, the process of developing a national consensus-based framework on preferred assessments, interventions, and PE-materials for young patients with ABI (4-25 years old) and their families was described. This is the first known study to describe the consensus-building process on a national scale across physiatrists and healthcare professionals to optimize and harmonize rehabilitation treatment for the pediatric ABI population.

Prior to the consensus meeting of this study, 136 different assessments and 39 interventions were used in the rehabilitation treatment of young patients with ABI and their families in the Netherlands, many of which were only used by a few healthcare professionals across RCs. Many of the assessments and interventions were generic and not specifically developed for the target group. This necessitates employing assessments to pinpoint the specific ICF domains where daily life problems occur.[31] Selecting the best suitable assessments to evaluate treatment outcomes for specific daily life problems in young patients with ABI can facilitate this need.

In terms of assessments in the field of psychology, only the 'battery for neuropsychological testing' (in Dutch: neuropsychologisch onderzoek, NPO) was proposed in the Delphi rounds by the participating psychologists. A national consortium of psychologists and physiatrists had already reached consensus on the use of this testing battery which contains tests to assess cognitive and mental functioning for the population of young patients with ABI in rehabilitation. This test battery was also described and recommended in the Dutch standard of care,[15] which was also the only specific assessment that was described in this standard of care.

Through the Delphi study consensus was reached on 37 assessments that covered all domains of the ICF model.[31] It is expected that this set is suitable for measuring the complete range of possible daily life problems and patient functioning and evaluating interventions in the ABI patient population. Many of these listed assessments were psychometrically tested and used among young patients with a wide variety of diagnoses in general pediatric rehabilitation.[16,17] However, most assessments were not psychometrically tested for the specific pediatric ABI patient population in rehabilitation. Nevertheless, a consensus-based framework of assessments can be used as a tool to potentially diminish practice variation and to help healthcare professionals with selecting the best suitable assessments for the target group. With confirmation of all participating Dutch RCs, this framework will be used in the future continuously which provides the opportunity to gather evidence on the use of the assessments not specifically designed for ABI.

In line with the assessments, interventions focusing on ABI-related consequences that align with diagnosis- and age-specific treatment are crucial for effective rehabilitation treatment.[13,21-25] The use of evidence-based interventions by healthcare professionals in various patient groups, including children with moderate/severe TBI and adult stroke, has been documented in the literature (e.g., cognitive behavior therapy, graded activity training, and the ABI-challenge assessment).[13,23,25] Prior to the current study, healthcare professionals used a wide variety of treatment interventions, and a large variation was seen across RCs in the Netherlands. The Delphi study resulted in a consensus on 25 interventions that covered the whole range of ICF domains.[31] Consequently, future research should investigate the optimal fit of currently proposed interventions for patients with specific ABI-related problems (e.g., cognitive fatigue, participation restrictions or social/emotional problems) and in specific age groups (e.g., adolescents that are in transition from childhood to adulthood).

The benefits of psychoeducation have been emphasized in earlier research and standards of care as being an important intervention to help young patients and their families to optimize functioning in daily life by better understanding the sequelae of ABI.[15,26,31] Psychoeducation is known to be effective before and during rehabilitation treatment for patients and their parents by for example enhancing knowledge on brain injury.[10] The Delphi study identified a list of PE-materials that can be used in rehabilitation treatment. Nevertheless, many of these materials were not specifically developed for the rehabilitation population of young people with ABI and their families. Additionally, a few of the PE-materials on the list included movies, apps, and websites, all of which are inherently transient and subject to change. It is crucial to continue developing and editing this list of materials in accordance with new insights into recovery and functioning after ABI of young patients in the rehabilitation setting.

Recommendations

To harmonize rehabilitation treatment across RCs in the Netherlands, consensus was reached on the implementation process of this national consensus-based framework by all the participating RCs (with their teams of physiatrists and healthcare professionals) that provide care for young patients with ABI and their families which is in line with the principles of VBHC.[27]

It is recommended that this framework is used as a tool during rehabilitation treatment to enhance selecting appropriate assessments in clinical practice. This was partly based on the flowchart by Swinkels et.al.[33]

Another recommendation arising from this Delphi study is that all disciplines involved during rehabilitation treatment should work together and look further than their own discipline to optimize the best possible multidisciplinary care for the young patient with ABI.

In line with VBHC principles,[27] as well as with literature in pediatric cerebral palsy rehabilitation,[18] a final recommendation is that the needs, wishes, and goals of individual patients with ABI and their families are important to consider when using this national consensus-based document as a healthcare professional.

Future research and development should focus on gathering evidence on the listed assessments, interventions, and PE-materials (in terms of psychometric properties and effectiveness) to make the consensus-based national framework more evidence-based.

Limitations

This study had a number of limitations. First, not all Dutch RCs providing rehabilitation treatment for young people with ABI participated in either the project "Participate?! Next Step" or the current Delphi study (14 out of 16 in total), which may have resulted in an incomplete picture/missed assessments, interventions, and PE-materials.

Secondly, most of the results of the Delphi study were applicable to the age group of 4-18 years. Only a few RCs that participated in the current study have a separate transition outpatient clinic through 25 years, in which the transitions from childhood and adolescence to adulthood get specific attention. Assessments, interventions, and PE-materials specifically for the age group of 18 to 25 years should be explored further, in line with recommendations to focus on age-appropriate care.[15,34]

Third, the care pathways, methods, and treatment offer in healthcare differs between countries making the results of this study less generalizable to ABI populations in other countries. Nevertheless, the outlines, procedures, recommendations, and limitations from the current study could be an example for similar research in other countries.

Fourth, when collecting assessments, interventions, and PE-materials for this framework, only healthcare professionals participated. In line with VBHC principles,[27] perspectives of patients and their parents on the content of rehabilitation treatment would also be important to take into account when optimizing the current national consensus-based framework.

CONCLUSION

This study developed a national consensus-based framework with preferred assessments, interventions, and PE-materials in outpatient rehabilitation treatment of young patients with ABI and their families in The Netherlands. This provides a valuable contribution to optimizing the care and support for these patients and their families. The framework can be used in clinical practice as a tool to enhance selecting appropriate assessments and setting goals at the start before, during, and after outpatient rehabilitation. The consensus-building process described in this study can be used as a blueprint by other research groups to create similar frameworks for other diagnoses. Future research should focus on substantiating and improving the current 'practice-based' national framework into an evidence-based guideline in terms of psychometric properties and effectiveness on the listed assessments, interventions, and PE-materials for the pediatric ABI population.

Declarations

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