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

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SECTION 2

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

CHAPTER 7

The structure of rehabilitation care for young patients with acquired brain injury: Similarities and differences among Dutch rehabilitation centers

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ABSTRACT

Purpose

To describe similarities and differences in rehabilitation care for young patients with acquired brain injuries (ABI) aged between 4 and 25 years among Dutch outpatient rehabilitation centers (RCs). Due to differences between RCs in terms of history/culture, team composition/expertise, and cooperation with network partners, variations between RCs are expected.

Methods

In this cross-sectional survey-study, professionals from RCs were invited to complete a 21-item questionnaire on the structure of rehabilitation for young patients with ABI (12 yes/no & 9 corresponding open-ended-questions). There were three topics: admission/discharge criteria (n=2&2), the organisation of rehabilitation (n=7&5), aftercare (n=3&2). Answers to yes/no questions were described and open-ended questions were thematically analyzed/categorized. The similarity in rehabilitation practice was defined as an item being present/described in ≥ 75% of the RCs.

Results

Rehabilitation professionals from 12 RCs participated. Similarities and differences were found regarding the structure of rehabilitation. Concerning the admission criteria (present in all RCs), "having a diagnosis of ABI" was seen as an important criterium in all RCs, where all other admission criteria were described differently. The discharge criterium "attainment of goals" was the only criterium found in ≥ 75% of the RCs. Regarding the organisation of rehabilitation, all RCs described the presence of specialized teams and diagnosis-specific consultation appointments. Differences were also found: the presence of "transition-teams" for young adults, and presence of general treatment programs (< 75% of the RCs). Concerning aftercare, similarities were found in the presence of structural end-reports, standard consults with rehabilitation physicians at discharge, and follow-up appointments. However, differences were seen in the timing between discharge and follow-up (six weeks-twelve months).

Conclusions

Despite similarities between RCs, differences were found in admission/discharge criteria, organisation of rehabilitation, and aftercare. Gaining insights into practice variation across RCs may help to reach consensus regarding 'best practice' on the structure of rehabilitation care for young patients with ABI.

Keywords: Rehabilitation Services; Health Care Organizations and Systems; Child and Adolescent Health; Comparative Health Systems/International Health

INTRODUCTION

Acquired brain injury (ABI) refers to any brain damage that occurs after birth and is worldwide a common condition, both in adults as well as in children and youth under the age of 25.[1,2] ABI can be divided into traumatic brain injury (TBI) and non-traumatic brain injury (nTBI).[1,2] In young patients (< 25 years old), TBI is the most common type (75% of all ABI) and is caused by external causes e.g., sports/traffic accidents and violence, whereas nTBI is the result of internal causes e.g., brain tumors and meningitis.[1,2] Young patients with ABI form a heterogeneous population concerning types of injury, severity, and long-term consequences.[3-5]

The care for patients with ABI, and more specifically young patients with ABI strongly depends on the severity and complexity of the brain injury.[6-9] When severe and more complex problems due to ABI are present, young patients initially receive care in the hospital, whereafter they are often admitted for either inpatient or outpatient rehabilitation treatment (depending on complexity of remaining problems).[7,10-12] Young patients with minor problems after ABI are often not hospitalized and usually receive treatment (i.e., physical therapy/ psychology) in primary care if indicated e.g., by general practitioners and/or medical specialists.[10,12,13] However, in case of persistent, more complex, or progressive problems, patients with a mild ABI are referred by medical specialists or general practitioners to outpatient rehabilitation services as well.[8-10,12,14,15]

In the Netherlands, care for young patients with TBI is described on its main features in a standard of care for children and adolescents (0-18 years old).[6] However, this standard of care does not specify the exact structures of rehabilitation care and leaves substantial room for variation, which may lead to differences in the delivery of care between rehabilitation centers (RCs).[16-19] Additionally, due to differences between RCs in terms of history and culture, composition and expertise team, and cooperation with network partners, variation between RCs is expected as well.

Such practice variation has been observed in the provision of rehabilitation in previous studies (adult stroke/arthritis rehabilitation) [20-22] but to date, it has not been studied in pediatric ABI rehabilitation in the Netherlands. If not explained by the case mix, practice variation could possibly be a signal of suboptimal care for patients (as described in previous studies).[20-22]

With the description and comparison of the provision of care across organizations, it is important to consider the context, structure, process, and outcome of care. Based on such

insights, specifically for the rehabilitation setting, frameworks and quality of care indicators were developed to evaluate quality of care for patients for several diagnoses.[16-24] Regarding the structure of rehabilitation care, regional differences were found in admission and discharge criteria for rehabilitation treatment, differences in care pathways, experience/knowledge of professionals, and referrals to other care facilities.[20-22]

It is not known whether and to what extent there are differences among RCs in the Netherlands in the structure of care for the population of young patients with ABI. Investigating potential similarities and differences could reinforce collaborations between RCs and targeting and reducing unwanted practice variations (if any) could be beneficial for the young ABI population in the Netherlands. Therefore, the aim of this study is to explore similarities and differences (variations) in the structure of care for young patients with ABI (4-25 years old) across Dutch RCs.

METHODS

Design

A cross-sectional survey study on the structure of outpatient rehabilitation for young patients with ABI.

Setting

The current study was part of a multicenter project: "Participate?! Next Step" (2021-2023) among Dutch RCs. This project aimed to optimize care for young patients (aged 4-25 years old) with ABI in the Netherlands among Dutch RCs. It was initiated by a project group, consisting of a PhD candidate (first author), and four senior researchers (second, third, and the last two authors) from Basalt Rehabilitation Center (The Hague, The Netherlands). The Medical Ethics Committee of the Leiden University Medical center (P15.165-addendum-1.0) and all local research committees of participating RCs approved the study.

Procedure

To provide an overview of the structure of rehabilitation care for young patients with ABI, the project group formulated an online questionnaire that was based on questionnaires from previous studies that investigated practice variation in terms of admission/discharge criteria, organization of rehabilitation, and aftercare.[20,21] Questions were adjusted and specified to focus on the structure of care for young patients with ABI in the outpatient rehabilitation setting. The questionnaire was formulated in Dutch and was first pilot tested by the project group (and adjusted where necessary). Thereafter, it was sent to participants

through an e-mail-link, using 'Castor' (Electronic-Data-Capture). It consisted of 21 questions (see Appendix 1). Twelve questions could be answered with: 'yes'/'no' and nine 'open answer questions' to request more details on the topics of interest. Questions were divided into 3 topics: the availability of admission/discharge criteria for rehabilitation treatment (n=2 yes/no questions & 2 open-ended questions), the organization of rehabilitation (n=7&5), and aftercare (n=3&2).

Participants

All RCs participating in the project were asked to appoint one or two of their healthcare professionals currently working with children with ABI to function as representatives in the project "Participate?! Next Step". Representatives were healthcare professionals:

- with experience with the target group,
- who were well informed about the way the care for the target group is organized in their team,
- that were willing to answer an online questionnaire.

The representatives were invited by e-mail to answer the online questionnaire. The project group encouraged them to involve their colleagues to answer all questions adequately on behalf of their RC (they mandated their RC as a whole).

Data Collection/Analyses

After the questionnaires were filled out by the participants, the completeness of the answers was verified. The first author asked participants to supply more information in case of incomplete answers. The 12 questions that could be answered with 'yes/no' were analyzed using descriptive statistics (presented as numbers (n) and percentages (%)). The nine 'open-ended answers' were qualitatively analyzed using thematic-analyses-methods.[25] First, open-ended answers were visually screened and merged into tables by the first author. When no additional information was given in an open-ended answer, it was noted as not applicable (NA) and not further analyzed. Thereafter, homogeneity of descriptions was noted per question, and thematic syntheses were formed.[25] The project group individually reviewed these syntheses, and after reaching consensus, they noted the numbers/percentages of themes per open-ended answer, enabling the objective identification of common themes.

Since levels of agreement in studies regarding 'similarities' are not clearly defined, the project group set these a priori at ≥ 75% in this study.[26] In case of < 75% agreement, it was considered a difference in structure (a practice variation). Finally, to present the results, all questions and answers were translated into English (and checked by a native-English speaker).

RESULTS

Fourteen representatives from 12 RCs in the Netherlands (Figure 1) answered the questionnaire on behalf of their RC. All representatives stated that they filled out the questionnaire with the help of their colleagues, resulting in the minimization of the chance of a response bias. These representatives were healthcare professionals, including one rehabilitation physician, one physical therapist, four psychologists, six occupational therapists, and two speech therapists.

Figure 1. Participating rehabilitation centers that provide outpatient rehabilitation for young patients with ABI in the Netherlands.

Participating Rehabilitation Centers: [1]Heliomare, Wijk aan Zee; [2]Reade, Amsterdam; [3]de Hoogstraat, Utrecht; [4]Basalt, The Hague; [5]Rijndam, Rotterdam; [6]Revant, Breda; [7]Revalidatie Friesland, Beetsterzwaag; [8]Vogellanden, Zwolle; [9]Roessingh, Enschede; [10]Klimmendaal, Arnhem; [11]Libra, Eindhoven; [12]Adelante, Valkenburg.

Admission/discharge criteria in pediatric ABI rehabilitation

All RCs (n=12, 100%) reported the presence of admission criteria in pediatric ABI rehabilitation treatment (see Table 1a, and Table 1b). However, differences were seen in four out of five descriptions of admission criteria, where the only similarity (> 75%) was seen regarding the criteria of "A diagnosis of ABI must be present" for starting treatment. Differences were seen regarding criteria that described that "participation restrictions had to be present in daily life" (n=5, 42%), "the patient/parents needed to have clear guiding-questions" (n=5, 42%), "patients/parents had to be in need of multidisciplinary rehabilitation treatment" (n=5, 42%), and "patients had to have sufficient mental and/or physical capacity before starting treatment" (n=3, 25%).

Table 1a. Similarities and differences in the presence of admission and discharge criteria in rehabilitation treatment in 12 Dutch ABI specialized Rehabilitation Centers

Presence of:	Answer (closed)	n (%)	Similarity#
Q1. Admission criteria	Yes	12 (100%)	Yes
	No	0 (0%)	
Q3. Discharge criteria	Yes	12 (100%)	Yes
	No	0 (0%)	

Q: Question. n: number. #similarities between centers: 'Yes' meaning that more than 75% of the centers provided the same answer and 'No' (differences) meaning that less than 75% of the centers provided the same answer.

Table 1b. The description of admission and discharge criteria in rehabilitation treatment in 12 Dutch ABI specialized Rehabilitation Centers

Description	Answer (open-ended*)	n (%)	Similarity#
Q2. Description of admission criteria	A diagnosis of ABI	12 (100%)	Yes
	Patients must have participation restrictions in daily life	5 (42%)	No
	Patients/parents need to have clear guiding questions	5 (42%)	No
	Requirement/need for multidisciplinary rehabilitation treatment	5 (42%)	No
	Mental and/or physical capacity of the patient needs to be sufficient	3 (25%)	No
Q4. Description of discharge criteria	Attainment of rehabilitation goals	10 (83%)	Yes
	Insufficient progress or no progress at all in achieving goals	3 (25%)	No
	Aftercare needs to have been arranged	5 (42%)	No

Q: Question. n: number. #similarities between centers: 'Yes' meaning that more than 75% of the centers provided the same answer and 'No' (differences) meaning that less than 75% of the centers provided the same answer. *Theme of description/explanation: synthesis through answers provided by the healthcare professionals from the 12 participating RCs.

All RCs (n=12, 100%) mentioned the presence of discharge criteria in paediatric ABI rehabilitation treatment. Across RCs, similarity was seen in the description of one discharge criterium i.e., ten RCs used the criterium "attainment of rehabilitation goals" (83%). Differences were seen across RCs regarding the criterium that patients had to stop treatment when they had "insufficient progress/no progress at all in achieving goals" (n=3, 25%) and that "aftercare needs to have been arranged" (n=5, 42%).

Organization of rehabilitation treatment

Regarding the organization of rehabilitation (Table 2a, and Table 2b), all RCs (n=12, 100%) described the presence of a team specialized in pediatric ABI treatment consisting of rehabilitation physicians, psychologists, physical therapists, occupational therapists, speech therapists, and social workers. Ten RCs (83%) also described other disciplines (e.g., nurses, creative therapists) being part of the team.

There were similarities found in the presence of an ABI-specific consultation appointment for new patients with a (suspected) ABI (n=10, 83%), carried out by a rehabilitation physician specialized in (pediatric) ABI (n=10, 83%).

All RCs (n=12, 100%) used age cut-off points for allocating patients to pediatric or adult rehabilitation teams, yet there were no unanimous cut-off points across RCs. The following age cut-off points were used: 4-18 years old (n=7, 58%) and 4-20 years old (n=5, 42%).

Table 2a. Similarities and differences in the presence of the organization of treatment in 12 Dutch ABI specialized Rehabilitation Centers

Presence of	Answer (closed)	n (%)	Similarities#
Q5. Specialized teams	Yes	12 (100%)	Yes
	No	0 (0%)	
Q7. Consultation appointments	Yes	10 (83%)	Yes
	No	2 (17%)	
Q9. Age cutoff points for pediatric versus adult treatment	Yes	12 (100%)	Yes
	No	0 (0%)	
Q11. Teams or programs for young adults	Yes	8 (67%)	No
	No	4 (33%)	
Q13. General ABI treatment program	Yes	8 (67%)	No
	No	4 (33%)	
Q15. Standard last consults	Yes	12 (100%)	Yes
	No	0 (0%)	
Q16. Structural end reports	Yes	11 (92%)	Yes
	No	1 (8%)	

Q: Question. n: number. #Similarities between centers: 'Yes' meaning more than 75% of the centers provided the same answer and 'No' (differences) meaning less than 75%.

Four RCs (33%) described the presence of 'transition teams' where adult patients between 18-25 years old receive age-appropriate care with a focus on their transition from childhood to adulthood.

Furthermore, differences were seen in the presence of a general ABI treatment program where only 8 (67%) described having such a program for the young adult age group (18-25 years old) and 8 (67%) for the whole population of young patients (4-25 years old) with ABI (n=8, 67%).

Table 2b. The description of the organization of treatment in 12 Dutch ABI specialized Rehabilitation Centers

Description		Answer (open-ended*)	n (%)	Similarities#
Q6.	Description of disciplines	Rehabilitation physicians, Psychologists, Physical therapists, Occupational therapists, Speech therapists, social workers	12 (100%)	Yes
		Other disciplines[1]	10 (83%)	Yes
Q8.	Consultation with whom	With a specialized rehabilitation physician	10 (83%)	Yes
Q10.	Description of age cutoff points	18 years old[2]	7 (58%	No
		20 years old[2]	5 (42%)	No
Q12.	Specification of teams programs	A program for young adults is being developed	1 (8%)	No
		A 'transition team' for adolescents/young adults exists	3 (25%)	No
Q14.	Description of availability[3]	NA[3]	NA[3]	NA[3]

Q: Question. n: number. *Theme of description/explanation: synthesis of answers by participants. #Similarities between centers: 'Yes' meaning more than 75% of the centers provided the same answer and 'No' (differences) meaning less than 75%.
[1] Nurses, music therapists, psycho-motor therapists, teachers specialized in youth with ABI, cognitive trainers, movement agoges, psycho-diagnostic staff members, rehabilitation technicians, exercise instructors, creative therapists, pedagogues, dieticians, clinical linguists, mental health /cognitive therapists, activity therapists, and psychiatrists.
[2] Young adults >18 or 20 sometimes receive pediatric rehabilitation when appropriate and/or when indicated.
[3] In case of the description of availability, no additional information was given after Q13: the presence of a general ABI treatment program.

Aftercare in pediatric ABI rehabilitation

Many similarities were found between RCs in the aftercare (Table 3a, and Table 3b) where RCs mentioned the presence of standard last consults with rehabilitation physicians before ending the rehabilitation program (n=12, 100%) and the presence of structural end reports (n=11, 92%).

All RCs (n=12, 100%) mentioned the presence of a structural follow-up appointment for the patient/parents after the rehabilitation program has ended. However, variations were seen regarding the time between discharge and follow-up ranging from 6 weeks-12 months, as well as regarding the frequency of follow-up: either annually or at 'transition moments' e.g., change of schools, from school to work.

All RCs (n=12, 100%) mentioned structural referrals to regional (care) facilities that support follow-up for the patient when indicated, yet the description of the actual reasons for referral, as well as structural cooperation with regional (care) facilities (e.g., primary care) in the follow-up process for the patient/parents, varied between RCs.

Table 3a. Similarities and differences in the presence of aftercare in 12 Dutch ABI specialized Rehabilitation Centers

Presence of	Answer (closed)	n (%)	Similarities#
Q16. Structural follow-up appointments	Yes	12 (100%)	Yes
	No	0 (0%)	
Q19. Structural referral to primary care[1]	Yes	12 (100%)	Yes
	No	0 (0%)	
Q21. Structural cooperation with primary care[1]	Yes	6 (50%)	No
	No	6 (50%)	

Q: Question. n: number. #Similarities between centers: 'Yes' meaning more than 75% of the centers provided the same answer and 'No' (differences) meaning less than 75%.
[1]When aftercare is indicated/appropriate.

Table 3b. The description of aftercare in 12 Dutch ABI specialised Rehabilitation Centers

Description	Answer (open-ended*)	n (%)	Similarities#
Q17a. Follow-up appointment with whom	Rehabilitation Physician	12 (100%)	Yes
	Psychologist	2 (17%)	No
Q17b. Time between discharge and follow-up	After 6 weeks[1]	2 (17%)	No
	After 3 months[1]	3 (25%)	No
	After 6 months[1]	3 (25%)	No
	After 12 months[1]	4 (33%)	No
Q17c. Frequently of follow-up	At transition moments (e.g., change of schools, from school to work)[1]	2 (17%)	No
	Once a year[1]	6 (50%)	No
Q20. Reasons for referral to primary care[2]	If treatment can be addressed by one discipline (no more need for multidisciplinary care)	6 (50%)	No
	If treatment/support is desirable closer to home	6 (50%)	No

Q: Question. n: number. *Theme of description/explanation: synthesis of answers by participants. #Similarities between centers: 'Yes' meaning more than 75% of the centers provided the same answer and 'No' (differences) meaning less than 75%.
[1]The timing and continuation of follow up appointments is in accordance with the patient/parents.
[2]When aftercare is indicated/appropriate.

DISCUSSION

This study found both similarities and variations among 12 Dutch RCs offering rehabilitation for young patients with ABI. Similarities regarding the presence of admission and discharge criteria, specialized teams, and structural follow-up were present in all RCs. Considerable differences were found as well, specifically regarding the description of the structure of rehabilitation care. Insights into similarities and differences may help reduce practice variation and optimize the quality of care for young patients with ABI. Here we discuss the implications of similarities and variations found in our study and provide recommendations for clinical practice and future research.

The description and use of admission and discharge criteria is considered important in clinical practice. Such criteria optimize resource allocation, ensure consistent patient treatment, promote patient safety, and enhance communication among healthcare professionals. Adhering to these criteria could enhance the quality of care within RCs. The importance of the description and use of admission and discharge criteria was also underlined in previous research.[6,16-18,20] Although all RCs in our study reported the presence of admission and discharge criteria, substantial differences in their actual descriptions were found. This is in line with previous studies.[21,22] A large variation (i.e., only mentioned by 5 RCs) was found in the admission criterium that "patients need to have participation restrictions in daily life". This variation is remarkable because optimizing participation is considered one of the ultimate goals of pediatric rehabilitation.[27,28]

The lack of generalized admission criteria that could be used in all RCs that provide pediatric ABI rehabilitation could be due to the heterogeneity of the population, although we have not investigated the cause of this variation. In addition, the attainment of rehabilitation goals, which is highlighted in the literature,[29] was considered an important discharge criterion among most RCs as expected, although this was not mentioned by all RCs. In line with previous literature that found variations in admission and discharge criteria in rehabilitation (adult stroke/arthritis populations),[21,22] we recommend reaching national consensus on clear and explicit criteria.

Regarding the organization of rehabilitation, the data collected among Dutch RCs show similarities and considerable differences as well. RCs were consistent in the need for specialized teams, with a wide variety of ABI-specific expertise. All RCs noted that they had a permanent team specialized in pediatric ABI. Yet, a remarkable finding was that despite the specialized teams being present in all RCs, not all teams had a general treatment program with specific outcome measures and interventions that would suit the target group

present. The absence of treatment program protocols could not only result in variations between RCs but also between team members within an RC. The lack of treatment program protocols in some RCs was also in line with the findings of previous studies that investigated practice variation.[21,22] Access to a treatment program protocol or guideline could reduce variation within teams and between RCs, whilst keeping the individual needs and wishes of patients (and their families) in mind. However, a national treatment program that could be used in all RCs when treating this population is lacking to date. Therefore, the creation of a national treatment program/guideline for the target group in outpatient rehabilitation is recommended.

While all RCs used age cut-offs to determine whether a young patient should be treated in a pediatric-appropriate or adult-appropriate rehabilitation setting, results showed variations in the cut-off-points across RCs (58% used 4-18 years as cut-off-point, 42% 4-20 years old). This could be due to the fact that some patients between 18 and 20 could better fit in a pediatric setting and some in an adult setting, based on their current needs and goals or purely based on age regardless of needs and goals.

Some RCs have “transition-teams”, to emphasize age-appropriate care for young adults where the focus lies on their transition from childhood to adulthood in relation to their ABI. Despite the importance of delivering age-appropriate care,[30] this was only seen in four RCs. Even though we do recognize that some RCs might not have the team/treatment capacity to organize this, we recommend focusing on more age-appropriate care.

All RCs reported that there are standard consults where treatment is being evaluated before ending rehabilitation and that there are structural follow-up appointments with rehabilitation physicians. These physicians discuss with patients/parents if and which form of aftercare is appropriate. Some RCs mentioned that referring to care facilities closer to home was considered important. National standards of care/guidelines also describe that providing sufficient aftercare for patients (also young patients with TBI/ABI) is important.[6,19] Our results showed differences between RCs in terms of the timing and frequency of aftercare, as well as the place where this is provided. This could be due to the current focus of pediatric rehabilitation care lies on individual patients, where every ABI, family, and system of patients is unique. This is important to consider in decision-making. In line with previous research,[16-24] setting clear criteria regarding the place, timing, and frequency of aftercare based on age and type of injury instead of only looking at individual patients could help to optimize aftercare for this pediatric ABI population. Due to regional differences in care pathways across RCs in the Netherlands, it is important to first look into possibilities to strengthen criteria regarding the place, timing, and frequency of aftercare within each RC separately before reaching national agreements on this matter.

Strengths and limitations

To date, this is the first (Dutch) study that investigated similarities and differences (practice variation) between RCs regarding the care for young patients with ABI on a considerably large scale (12 out of 16 RCs in the Netherlands). A structured approach was used for identifying similarities and differences among RCs. The recommendations that were provided in this study provide useful insights whilst keeping differences in care pathways between regions in mind. This 'look behind the curtains' in 12 RCs could enable collaborations between RCs and could eventually help reaching consensus on rehabilitation structures that currently vary across RCs that provide care for young patients with ABI.

This study also had some limitations. In this study, we explored the way rehabilitation care for children with ABI is organized in different RCs in The Netherlands. Therefore, we asked healthcare professionals how care is organized in the RC they work in. We have chosen to ask healthcare professionals because they have the role in the delivery of care. This may be a limited perspective since actively involving managers and policymakers might have resulted in a broader view. Future research could, for instance, use focus groups to potentially obtain a broader view per RC. Focus groups are a valuable research method that provides deeper insights and diverse perspectives, involving patients and relatives to enhance understanding of interventions' impact and outcomes. Furthermore, only Dutch RCs were included in the present study, thereby limiting outcomes in terms of generalizability for the care for young patients around the globe. However, this study provides information on how to obtain information regarding similarities and differences between RCs which could be useful for other countries/regions to look into their own possible practice variations.

Second, the answers that were provided by the participants could possibly be influenced by factors that were beyond the boundaries of their profession such as the financial influence of insurance companies and admission criteria of other care facilities in the aftercare process. The interplay between these factors should be further investigated.

CONCLUSION

If not explained by the case mix due to the heterogeneity of the population, exploring differences (variations) among RCs could help in reaching the goal of providing the best possible care for young patients with ABI. If RCs uniformly adhere to the same criteria and structure of treatment, this can support effective and timely referrals to RCs by medical specialists and general practitioners if indicated. Acknowledging differences that were

found among RCs in this study can be considered the first step to further optimize care. Focusing on reaching national consensus among RCs to reduce variations and uniform treatment in terms of content to optimize rehabilitation care for young patients with ABI should be the next step. Finally, joint frameworks about the organization and content of rehabilitation treatment can help clinicians/researchers with clinical reasoning and decision-making.

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Conflicts of interest

The authors of this study have no conflict of interest to declare.
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Appendix 1. Questionnaire to study the structure of ABI rehabilitation for young patients divided into topics, questions, and the way they could be answered

Topic 1	**Admission/discharge criteria for rehabilitation treatment**		
Question (Q)		**Closed answer (yes/no)**	**Open-ended (description)**
Q1.	Are there admission criteria before starting the rehabilitation treatment program?	X	
Q2.	Give a description of which admission criteria.		X
Q3.	Are there discharge criteria for ending the rehabilitation program present?	X	
Q4.	Give a description of which discharge criteria.		X
Topic 2	**The structure of rehabilitation treatment**		
Question (Q)		**Closed answer (yes/no)**	**Open-ended (description)**
Q5.	Is there a team specialized in pediatric ABI treatment present?	X	
Q6.	Give a description of which disciplines are in these teams (if any).		X
Q7.	Is there a specific consultation appointment for new pediatric patients with ABI present?	X	
Q8.	Give a description with whom the specific consultation hour is (if any).		X
Q9.	Does the RC use age cutoff points* in age groups for patients with ABI?	X	
Q10.	Give a description of which age cutoff points (if any).		X
Q11.	Is there a general program for the young adult age group (18-25 years)?	X	
Q12.	Give a specification of this program (if any).		X
Q13.	Is there a general ABI treatment program?	X	
Q14.	Give a description of availability (if any).		X
Q15.	Is there a standard last consult with the rehabilitation physician before ending the rehabilitation program?	X	
Q16.	Is there a structural end report with outcomes from the start and throughout the whole rehabilitation program/trajectory?	X	
Topic 3	**Aftercare**		
Question (Q)		**Closed answer (yes/no)**	**Open-ended (description)**
Q17.	Is there a structural follow-up appointment for the patient/parents after the rehabilitation program has ended?	X	
Q18a.	Give a description of with whom the patient/parents are receiving a structural follow-up appointment (if any).		X
Q18b.	Give a description of how much time this usually takes place after discharge (if any).		X
Q18c.	Give a description of how frequently this usually takes place (if any).		X
Q19.	Is there a structural referral to regional (care) facilities that support follow-up for the patient?	X	
Q20.	Give a description of reasons for referral to regional (care) facilities that support follow-up for the patient (if any).		X
Q21.	Is there structural cooperation with regional (care) facilities present in the follow-up process?	X	

* The use of age cutoff points for patients to differentiate from