Participation of children and youth with acquired brain injury

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Chapter 4

Determinants of participation of youth with Acquired Brain Injury: a systematic review

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Submitted

ABSTRACT

Objectives Participation is considerably restricted in children and adolescents with acquired brain injury (ABI) as compared to their healthy peers. This systematic review aims to identify which factors are associated with participation in children and adolescents with ABI.

Methods A systematic search in Medline and various other electronic databases from January 2001 to November 2012 was performed. All clinical studies describing determinants of participation at least one year after the diagnosis of ABI by means of one or more predefined instruments in patients up to 18 years of age were included. Extracted data included study characteristics, patient characteristics, participation outcome and determinants of participation (categorized into: health conditions (including characteristics of ABI), body functions and structures, activities, personal factors and environmental factors). The methodological quality of the studies was evaluated based on three quality aspects (selection, information and statistical analysis bias) and scored as low, moderate or high.

Results Five studies, using an explicit participation outcome measure were selected after review, including a total of 1172 patients, with a follow-up ranging from 1 up to 84 months. Three studies included patients with a traumatic or a non-traumatic brain injury and 2 studies with only patients with TBI. The factors which were most consistently found to be associated with more problems in one or more dimensions of participation were greater severity of ABI, problems in movement functions, cognitive functioning, behavioural functioning and sensory functioning, problems in accessibility and design of the physical environment. In addition, a more supportive nurturing and parenting style, higher household income, more acceptance and support in the community, more availability of special programs and special services were associated with less participation problems. The overall methodological quality of the included studies was moderate in all 5 studies.

Conclusion This systematic review shows that only a few, moderate quality, studies on the determinants of participation after ABI using recommended explicit measurement instruments are available. Several factors in the ICF components health condition, body functions and structures and environmental factors were consistently found to be associated with participation. More methodologically sound studies using the recommended explicit outcome measures, a standardized set of potential determinants and long term follow-up are suggested to increase the knowledge on participation in children and youth with ABI.

INTRODUCTION

Acquired brain injury (ABI) refers to any damage to the brain that occurs after birth,[1] and may have traumatic (traumatic brain injury, TBI) or non-traumatic causes (non-traumatic brain injury, NTBI). Among children and adolescents ABI is a common condition, as well as the leading cause of death[2] and permanent functional limitations in functioning.[3-10]

So far, studies on the outcome of TBI in children and adolescents have been mainly concerned with physical, cognitive and behavioural functioning and to a lesser extent with participation.

According to the International Classification of Functioning, Disability and Health (ICF) of the World Health Organization (WHO),[11] participation can be defined as the nature and extent of a person's involvement in meaningful life situations at home, school, work and community life.[3]

Regarding the extent and nature of participation restrictions a few literature reviews on participation outcome after paediatric ABI are available, including one on behavioural outcome and adaptive functioning,[4] one on community integration interventions[8] and two narrative reviews on participation outcome measures.[9,10] Overall it was found that significantly more children and adolescents with ABI had limitations in social relations, peer social-play at school and engagement in organized community, social and civic areas of life than their healthy peers.

Most studies included in these reviews were focused on TBI and/or the age group up to 15 years old. Moreover, some of the studies concerned small populations (n < 50), had a specific focus within participation (participation at home or at school or in recreational time) and/or a follow-up time of one year or less.[4,8-10] As far as the determinants of participation after paediatric ABI are concerned, the literature has thus far not been systematically summarized. In a number of studies addressing the following factors were reported to be significantly associated with participation restrictions after ABI: greater injury severity;[3,5,6,12,13] bilateral injury and frontal end temporal lesions;[14] presence of neurological complications;[3,15] physical, cognitive and social emotional impairments;[15] limited pre-injury competences;[6,16] pre-injury psychiatric disorders;[13] younger age at injury;[3] worse pre-injury or actual family functioning;[12] lower socio economic status;[16] restrictions in physical, social and attitudinal environment;[3] and limited availability of adequate information, programs/services.[17] Given the absence of a systematic synthesis of the literature on participation determinants after paediatric ABI the aim of the present study was to systematically review the literature on factors associated with participation after paediatric TBI and NTBI.

METHODS

Search Strategy

In cooperation with a trained librarian (J.W.S.) a search strategy was composed (see Appendix 1). The search strategy consisted of a combination of two main concepts: Participation (social participation, participation in leisure time, community, school, domestic life, interpersonal interactions and relationships, major life areas, community, social and civic life); and Acquired Brain Injury (e.g. Traumatic Brain Injury; Stroke; Brain Tumour), and was restricted to children and youth in the age group up to 18 years old: children (0-12 years), adolescents (13-18 years), youth (15-23 years), or paediatrics (0-18 years).[18] The search strategy was developed for PubMed and subsequently adapted for use in other databases, including EMBASE (OVID version), Web of Science, COCHRANE Library, CINAHL (EbscoHost version), PsycINFO (EbscoHost-version), Academic Search Premier and ScienceDirect. Original clinical studies, irrespective of the study design, were selected. Restrictions included in the electronic search pertained to the language (papers in English) and studies in humans. The search was performed on November 12, 2012.

Data collection and analysis

We defined 4 steps in the selection of studies, data extraction and analysis. All steps were performed by three of the authors independently (A.J.K., R.G., J.M.). In case of disagreement about the selection or data extraction, consensus was reached through discussion. If consensus between the two authors was not achieved, a final decision was made by a third author (T.V.V.).

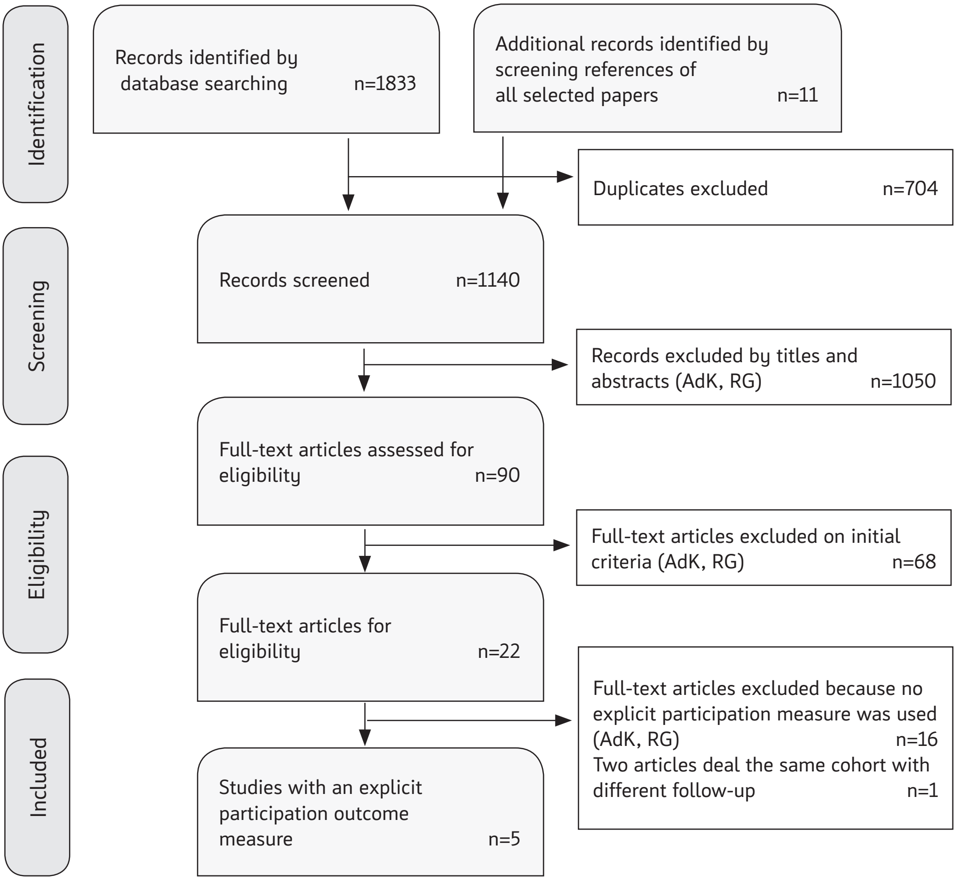
Step 1: Screening of titles and abstracts

First, all duplicates in the results of the electronic search were removed. The remaining titles and abstracts were included if the following criteria were met: (1) original clinical study with at least 10 patients; (2) providing of quantitative information on participation (irrespective of the outcome measure) at least 12 months after the diagnosis. Comprehensive outcome measures, such as quality of life instruments, were only considered to be participation measures if the participation was described as a separate dimension; and (3) describing factors associated with participation at least 12 months after the diagnosis. In case a study also included adult patients also, it was only selected if results on the participants in the age group 0-18 years old were reported separately. Studies which were solely aimed at the methodological properties of specific measurement instruments were excluded.

Step 2: Selection of full-text papers

Titles and abstracts identified as potentially eligible were selected for full-article review (see figure 1). If an abstract was not available, the full-text paper was requested. For the screening of the full-text papers the abovementioned criteria were again used. In Step 2, two additional inclusion criteria were used to be able to compare and summarize results: (4) using at least one instrument to measure participation which is included in one or more published lists of recommended explicit measurement instruments for participation in children with ABI (see Appendix 2)[9,12,19] and (5) using the results of at least one recommended explicit outcome measure as dependent variable in the data analysis.

Figure 1 Flow Chart



Finally, the references of all selected papers and systematic reviews included in the yield of the search strategy were checked for potentially eligible studies that were not identified in the original search strategy. The titles and abstracts of these references were screened using the abovementioned selection procedure.

If one study was described in several papers, the various papers were considered as one study, with multiple references.

Step 3: Data extraction

For all selected full-text papers the following study characteristics were systematically extracted: title, first author, year of publication, country where the study was conducted, study design (retrospective, prospective or cross-sectional) and duration of follow-up. The patient characteristics registered were: the number of subjects in the study, diagnosis, inclusion criteria, time since onset of ABI and socio-demographic characteristics (age, sex) were registered.

For the participation outcome, we noted the time of the follow-up assessment and the instruments used to measure participation.[9,19] In addition, the reported actual results on participation outcome regarding these participation measures were extracted.

For the determinants of participation, variables were categorized according to the ICF-CY[11] in Health Condition (e.g. injury characteristics; code hc); Body Functions and Structures (physiological functions of systems and structure or anatomical parts; code b); Activities (execution of an action or task by an individual; code d); Environmental Factors (physical, social and attitudinal environment; code e); and Personal Factors (individual background, e.g. gender, race; code p). Determinants were categorized to the most precise ICF component (e.g. b Body Functions), chapter (e.g. b1 Mental Functions) or category (e.g. b126 Temperament and personality functions)[11] according to the established ICF linking rules,[20] if they were associated with one or more dimensions of participation in social interactions and relations, major life areas and community, social and civic life. In the prospective studies data extraction of results of analyses of associations between potential determinants and participation outcome were based on data of the final (follow-up) assessment. Factors were rated as being consistently associated with participation if a statistically significant association was found in more than 1 study and no statistically significant associations in the opposite direction were seen.

Step 4: Assessment of methodological quality

To assess the methodological quality of the included studies, we used a quality checklist employed in similar reviews but in other patient groups,[21] which was based on items described in a review of tools for quality assessment[22] and on a review of the quality of prognostic studies in systematic reviews.[23] Two authors independently assessed the quality of each study by scoring 15 items, divided into three categories: a) selection bias (items 1-6); b) information bias (items 7-18) and c) statistical analysis of potential determinants of participation (items 19-23). 'No information found' was reported as question mark and scored as 'bias or unclear'. Bias was considered present if more than 2 of the items within a category pointed in this direction. Particular emphasis was placed on the employment of a multivariate analysis of potential determinants of participation. Finally, quality was rated high when no bias was scored in all 3 categories, moderate with bias in 1 or 2 and low with bias in all 3 categories.

RESULTS

Figure 1 presents the selection of studies. The initial electronic database search yielded 1833 records, wherein 11 records were added after screening the references of systematic reviews resulting from the initial search. After excluding 704 records which appeared in multiple databases, 1140 unique records were evaluated, based on title and abstract. Subsequently, with the first selection in step 1, 1050 records were excluded because they did not meet the inclusion criteria, and 90 full text papers were retrieved. In step 2, it was found that 22 full-text papers met the first 3 inclusion criteria.[24-45] After applying inclusion criteria (4) and (5), 16 studies were excluded as they did not comprise an explicit participation measure. The characteristics of these studies are presented in Appendix 3.
Finally, 6 papers meeting all inclusion criteria were selected. Two of these 6 papers concerned the same study[25,42] with only a different follow-up. The study with the longest follow-up was included in the review, thus finally 5 studies were included.[26,29,32,41,42]

Study characteristics

The characteristics of the 5 included studies[26,29,32,41,42] are presented in Table 1. Four studies[26,29,41,42] were from the North Americas, whereas one[32] was executed in Australia. Three studies had a cross-sectional design,[26,32,41] the other 2 studies had a prospective design.[29,42] Two studies[41,42] were concerned with TBI only, whereas the other 3 studies[26,29,32] included both patients with TBI and NTBI. Five different age ranges were used in 5 studies, varying in length from 12 to 19 years. One study[42] included children under the age of 4, whereas all studies included patients up to at least 18 years old. The number of (follow-up) measurements varied from 1 to 5, the time since the onset of injury ranged from 1 up to 84 months in all 5 studies. In one of the two prospective studies[42] the follow-up was up to 36 months after the onset of ABI. In one study the outcome of patients with TBI or NTBI were compared with healthy controls.[42]

Participation outcome

In table 1 the measurement instruments employed in the 5 selected studies are presented. The explicit participation measures included the Child and Adolescent Scale of Participation (CASP)[26,32,41,42] and the Children's Assessment of Participation and Enjoyment (CAPE).[29]
Two of the three cross-sectional studies both using the CASP, found that, depending on age group, 30-73%[26] and 25-75%[32] of children and youth were restricted in at least 1 participation domain (at home, at school or in community).

Table 1 Characteristics of 5 studies (6 papers), using explicit participation outcome measures, on determinants of participation after paediatric acquired brain injury

First author, country	Study design	Year of publication	Number of patients (TBI/NTBI/ controls)	Diagnosis	Follow-up post injury in months (range)	Participation measure		
						Explicit ABI[a]	Explicit general[a]	Implicit[b]
Bedell, USA[26]	Cross-sectional	2004	60 (38/22/0)	TBI + NTBI	42 (4-80)	CASP		PEDI, CASE
Wells, Canada[41]	Cross-sectional	2009	30 (30/0/0)	TBI	30 (12-60)	CASP		CASE
Galvin, Australia[32]	Cross-sectional	2010	20 (12/8/0)	TBI + NTBI	25 (4-84)	CASP		CASE
Rivara, USA[42]	Prospective	2012	926 (729/0/197)	TBI	1-3-12-24-36	CASP		ABAS-II, PedsQL, CASE, FAD
Anaby, Canada[29]	Prospective	2012	136 (113/23/0)	TBI + NTBI	8-12		CAPE	FAD, CASE

[a] according to Bedell, et al, 2007; van Tol, et al, 2011;

[b] according to Bedell, et al, 2007; van Tol, et al, 2011; Mc Cauley, et al, 2011

CASP=Child and Adolescent Scale of Participation; CAPE=Children's Assessment of Participation and Enjoyment; ABAS II=Adaptive Behaviour Assessment System - Second Edition; CASE=Child and Adolescent Scale of Environment; FAD=Family Assessment Device; FBII=Family Burden of Injury Interview; PEDI=Paediatric Evaluation of Disability Inventory (social functioning scale); PedsQL=Paediatric Quality of Life inventory (social subscale).

Participation restrictions were seen in social relations (50-80% at home, 55-80% with friends or at school, 65-80% in community), in major life areas (55-70% in educational activities, 50-65% in work activities) and structured community, social and civic life (47-60% in household activities, 30-45% in shop-manage money activities, 65-71% in managing daily schedule, 46-60% in using transportation), where all patients were missing adequate support and attitudes in environment.[41] Mobility or moving around was least restricted in and around home (30%), more problems were experienced in moving around in community (55%).[26, 32,41]

Two studies[29,42] had a prospective design. Rivara,[25,42] using the CASP, found significantly worse total participation scores at all 4 time points compared to a control group with arm injury. Anaby[29] examined the changes in level of participation over 1 year after return to school, using the CAPE to measure participation (social, physical and recreational) in out-of-school activities in children and youth with TBI and NTBI. In that study it was found that intensity (how often a child does an activity) scores were more likely to change over time than diversity (whether a child does an activity) scores.

Determinants of participation

Table 2 shows the results of the reported associations between various potential participation determinants and participation after paediatric ABI. Overall, a range of factors was evaluated, with most of the studies examining multiple independent variables. The dependent variables concerned social participation in play or leisure activities at home (CASP, CAPE), at school (CASP) and in community (CASP, CAPE), as well as participation at school or in work (CASP) and structured events in community, social and civic life (CASP, CAPE). Four studies[26,29,41,42] employed multivariate analyses.

The factors which were most consistently found to be associated with more problems in one or more dimensions of participation in the ICF-CY component Health Condition was a greater severity of ABI.[29,41,42] Type or cause of injury was consistently found not to have an impact on participation.

Concerning Body Functions and Body Structures, problems in movement functions, cognitive functioning, behavioural functioning and sensory functioning were significantly associated with more participation restrictions.

Regarding Environmental factors, problems in accessibility and design of the physical environment were significantly related to more participation restrictions. Moreover, a more supportive nurturing and parenting style, higher household income, more acceptance and support in the community, more availability of special programs and special services were associated with less participation restrictions.

None of the factors in the ICF components Activities and Personal Factors were consistently associated with participation outcome.

Table 2 Results of 5 studies on determinants of participation of children and youth with Acquired Brain Injury

Independent variables				
Health Condition[a]	**Body functions and structure[a]**	**Activities[a]**	**Environmental Factors[a]**	**Personal Factors[a]**
Greater severity of ABI -: 29*, 41*, 42*	MENTAL FUNCTIONS[b] (b140-b189[c]) Problems in cognitive functioning[d] -: 26*, 32 Problems in behavioural functioning -: 26*, 32 Problems in emotional functioning -: 26*	GENERAL TASKS/ROUTINES (d210-d299) Capacity +: 32	PHYSICAL ENVIRONMENT (e210-e299) Problems in accessibility, design -: 26*, 32, 41*	General health problems -: 26*
Type/cause of injury =: 26*, 29*, 32	SENSORY FUNCTIONS AND PAIN (b210-b229) Sensory functioning problems -: 26*, 32	MOBILITY (d410-d499) Capacity +: 32 = 26*	SUPPORT AND RELATIONS (e310-e399) Worse family functioning -: 29* = 42* Supportive nurturing and parenting style +: 32, 41* Higher household income (SES) +: 29*, 42* Higher parental education =: 42*	Younger age (at onset) -: 41* Longer time since onset -: 29* = 26*, 32 Older age (at follow up) -: 42*
Presence of neurological comorbidities =: 42*	VOICE AND SPEECH (b 310-b399) Speech problems -: 26*	SELF-CARE (d510-d599) Capacity +: 26*	ATTITUDES (e410-499) Acceptance and support in community +: 26*, 32, 41*	Race/Ethnicity =: 26*
	MOVEMENT RELATED FUNCTIONS (b710-b729) Problems in movement functions -: 26*, 32		SERVICES, SYSTEMS POLICY (e510-d599) Availability of special programs +: 26*, 32, 41* Availability of special services +: 26*, 32, 41* Length of stay in inpatient rehabilitation = : 26*	

According to the ICF-CY: a=component b=chapter c=code d=category

Relation can be + (positive) , meaning resulting in less participation problems, - (negative) meaning resulting in more participation problems or = (neutral) if relations were studied but not found

* multivariate analysis

Methodological quality of studies

Table 3 summarizes the results of the methodological quality assessment of the 5 included studies.

Table 3 Quality assessment of 5 studies on determinants of participation of children and youth with Acquired Brain Injury

First author, country (search number record)	Selection bias present[a]	Information bias present[a]	Statistical analysis bias present[a]	Total score	Level of quality[b]
Bedell, USA (484)	1	0	0	1/3	M
Wells, Canada (261)	1	0	0	1/3	M
Galvin, Australia (143)	1	0	1	2/3	M
Rivara, USA (55)	1	0	0	1/3	M
Anaby, Canada (36)	1	0	0	1/3	M

[a] 0= no bias present; 1= bias present or unclear

[b] H= high quality: no evidence for selection bias, information bias or analyses bias; M= moderate quality: one or two quality aspects rated as bias present or unclear; L= low quality: all three aspects rated as bias present or unclear

The methodological quality was rated as moderate in all 5 studies, mainly due to selection bias.

DISCUSSION

In this systematic review 5 studies on determinants of participation of children and adolescents after ABI were included, with 2 studies restricted to only TBI, and all studies having a moderate methodological quality.

These 5 studies showed that, 12-84 months after the onset of ABI, 25-80% of children and youth were restricted in at least 1 participation domain, while problems hardly decreased over time. In out-of-school time the intensity (how often a child does an activity) of activities was more likely to change over time than the diversity (whether a child does an activity).

With regard to participation outcome after paediatric ABI, the results of our study are comparable with available reviews:[4,8-10] problems pervasive,[26,32,38] not decreasing over time,[26,34,35,39] manifesting in social interactions and relations,[24-45] as well as in school[25,26,32,41,42] and engagement in organized community, social and civic areas of life.[24-26,29, 32,41,42] Analogy between the reviews, however, is limited due to essential differences, e.g. focus on 1 or several domains of participation.

The factors most consistently associated with one or more dimensions of participation in social interactions and relations, major life areas and community, social and civic life were: greater severity of ABI, sensory functioning problems (Health Condition); problems in movement functions, cognitive functioning, behaviour (Body Functions and Structure); problems in accessibility and design, higher social economic status and availability of special services en programs (Environmental Factors). No consistently associated factors were found in the ICF categories Activities and Personal Factors.

Results in the studies included in this review concerning the determinants of participation after paediatric ABI (Table 2) are comparable with literature: a greater severity of the injury,[3,5,6,12,13] the presence of impairments of physical, cognitive and behavioural functioning,[15] lower household income,[16] restrictions in physical, social and attitudinal environment.[17] Longer time since onset[7] and worse family functioning[12] were found as associated factor in 1 or more of included studies, but disputed in another. The included studies did not report an impact of the type of injury, length of stay in inpatient rehabilitation,[2] presence of comorbidities and problems in mobility[2] on participation after paediatric ABI.

Our review showed several additional or more specified associated factors, e.g. problems in sensory functioning and acceptance and support in community.

It should be noted that the included five studies differed considerably in participation domain (e.g. at home/school/community or home/community) and the selection of potential determinants (e.g. type of injury, neurological comorbidities, race/ethnicity). Relatively few studies included 'Activities' and 'Personal Factors' in the analysis of determinants of participation after paediatric ABI.

Overall, the methodological quality of the studies was moderate, due to potential bias in all three aspects of the instrument which was applied, with: 3 studies showed selection bias (especially lack of theoretical background or loss of patients in follow-up) and 1 presented statistical analysis bias (especially missing information on missing values). Included studies showed a great variety in age at inclusion, age range, number and time since onset of injury of (follow-up) measurements. It should be noted that some of the studies in our review had a cross-sectional and others a prospective design, so that the potential determinants in some cases were recorded directly after the onset of ABI and the outcome after follow up whereas in other cases all measurements (dependent and independent factors) were done at one time point. For the early identification of patients at risk for participation restrictions, it is important to have predictors which can be measured directly after the onset of ABI. Such predictors can only be derived from prospective studies.

Since there was an absence of systematic reviews of studies focusing on determinants of participation after paediatric ABI, our findings can only be compared with similar syntheses of the literature concerning children with other conditions, such as Cerebral Palsy[48-50] and other physical limitations.[51,52] In these studies participation was found to be associated with a variety of factors as well. Gross motor function, manual ability, limitations in mobility and communication are reported more consistently as associated with participation after CP[51,52] than after ABI (this review), as well as gender. Unlike after CP and other physical disabilities the present review showed that current (problems in) cognitive functioning and behaviour were associated with more participation restrictions after ABI.

This study has a number of limitations. First, we cannot draw reliable conclusions about causality: several independent factors are mutually influencing each other and moreover they were measured at the same point in time as the dependent factors in the cross-sectional studies. We did not attempt to pool data, as studies were very heterogeneous concerning study designs, patient selection and measurement methods. Inconsistent findings in this systematic review are probably due to large variation in age at inclusion, age range, number and timing of follow-up measurements, definition and focus on domain of participation, selection of instruments.

Another limitation is the limited number of 5 included studies. In the search strategy we included only studies in English, so that potentially eligible studies in other languages may have been missed.

In the selection process neither intervention, nor retrospective studies were found, possibly due to the strict inclusion criteria. Thirdly, only a small sample of children and adolescents with NTBI was included in the 3 selected papers, while determinants of participation outcome after TBI cannot be generalized across various aetiologies and of NTBI.[59] Finally, all studies were performed in Western countries, 4 in the North Americas and 1 in Australia, this limits broader generalization of results as well.

Therefore, we recommend international consensus on the definition of participation and the use of a minimum set of variables potentially related to participation and quality of life outcome, following recommendations of the inter-agency Paediatric TBI Outcomes Workgroup.[19] Then, further development and validation of ABI, domain and age specific participation outcome measures is required. Recently 2 explicit participation outcome measures have been developed as explicit participation outcome measure for children (5-17 years old): the youth report version of the Child and Adolescent Scale of Participation (CASP)[53] and the Participation and Environment Measure for Children and Youth (PEM-CY),[54] the latter for youth with or without disabilities, assessing parent reported participation frequency, extent of involvement, and desire for change in sets of activities typical for the home, school, or community. Similar initiatives are needed to more accurately identify and describe (determinants of) participation in order to augment current knowledge about participation after paediatric ABI and associated factors, and will guide efforts to develop timely and useful interventions for patients and family to maximize participation and quality of life, and minimize secondary problems commonly associated with ABI.[32]

Regarding the classification and interpretation of associated factors, the ICF appeared to be supportive to analyse and describe the studies included in this review, as suggested by others.[56-58] The ICF model serves to underscore the complexity, interrelated and dynamic nature of participation as well. It should be noted that linking of several ICF categories, e.g. aspects of communication (in b167 or d3), learning (in b1 or d1) and personality (in b126 or personal factors). Moreover, the distinction between general (d710-729) versus complex (d720-729) versus special (d730-779) interpersonal interactions is arbitrary. Some categories require specification regarding to paediatric ABI, e.g. in external factors (ICF code e) and family (e310) could be differentiated in impact and functioning, acceptance and attitudes, educational competencies and skills, communication and worries as specific and associated with functioning and disabilities of the child and adolescent.

CONCLUSION

In this systematic review on determinants of participation after paediatric ABI 5 studies using an explicit participation outcome measure were included, all of moderate quality. Therefore more studies are needed, based on consensus regarding the definition of participation and methods of measurement and on the set of potential determinants to be analysed, including large cohorts of children and youth in all age groups and different cause and severity of injury and employing a methodologically sound analysis.

Declaration of Interest statement

The authors report no conflicts of interest.

Appendix 1. Search Strategy Systematic Review: Determinants of participation among children and adolescents with Acquired Brain Injury (PubMed-version)

(((“Human activities”[majr] OR activity[ti] OR activities[ti]) AND (rehabilitation OR rehabilitat*)) OR ((participation OR “Interpersonal Relations”[majr] OR “Environment”[majr] OR “Social Adjustment”[majr]) AND (rehabilitation OR rehabilitat*)) OR ((participation NOT (“Consumer Participation”[mesh] OR “Patient Participation”[mesh] OR “Refusal to Participate”[mesh] OR “patient participation” OR “consumer participation” OR “client participation”))) OR (“home participation” OR “school participation” OR “social participation” OR “societal participation” OR “society participation” OR “community participation” OR “civic participation” OR “participation outcomes” OR “leisure participation” OR “recreation participation” OR “sports participation” OR “sport participation” OR “Social Participation”[Mesh] OR “Activities of Daily Living”[mesh] OR “Activities of Daily Living” OR “daily life” OR “daily living” OR participat*[ti] OR “Patient Participation”[majr])) AND (“Brain Injuries”[Mesh] OR “Brain Injury” OR “Brain Injuries” OR “Brain Lacerations” OR “Brain Laceration” OR “Cortical Contusion” OR “Cortical Contusions” OR “Post-Traumatic Encephalopathies” OR “Post-Traumatic Encephalopathy” OR “Posttraumatic Encephalopathy” OR “Brain Contusion” OR “Brain Contusions” OR “Traumatic Encephalopathy” OR “Brain Trauma” OR “Brain Traumas” OR “Traumatic Encephalopathies” OR Concussion OR Concussions OR “Contrecoup Injury” OR “Contrecoup Injuries” OR “Post-Concussion Syndrome” OR “Postconcussion Syndrome” OR “Traumatic Brain Hemorrhage” OR “Traumatic Brain Stem Hemorrhage” OR “Traumatic Cerebral Hemorrhage” OR “Traumatic Brain Hemorrhages” OR “Traumatic Cerebral Hemorrhages” OR “Traumatic Cerebral Haemorrhage” OR “Traumatic Cerebral Haemorrhages” OR “Diffuse Axonal Injury” OR “Diffuse Axonal Injuries” OR “Post-Traumatic Epilepsy” OR “Posttraumatic Epilepsy” OR Pneumocephalus OR “Shaken Baby Syndrome”) AND (“Child”[mesh] OR child[tw] OR children OR pediatric OR paediatric OR pediatrics OR paediatrics OR “Adolescent”[mesh] OR adolescence OR adolescent OR adolescents OR “Young Adult”[mesh] OR “young adult” OR “young adults” OR child*[tw] OR schoolchild*[tw] OR infan*[tw] OR adolesc*[tw] OR pediat*[tw] OR paediat*[tw] OR boy[tw] OR boys[tw] OR boyhood[tw] OR girl[tw] OR girls[tw] OR girlhood[tw] OR youth[tw] OR youths[tw] OR teens[tw] OR teenager*[tw] OR puberty[tw] OR preschool*[tw] OR juvenile[tw])

Appendix 2. Variables used in data extraction, according to the ICF-CY

Dependent (outcome) variables	Explicit participation measures; ABI specific Child and Adolescent Scale of Participation, CASP[1,2]
	Explicit participation measures; not ABI specific Assessment of Life Habits for Children, LIFE-H[1] Children's Assessment of Participation and Enjoyment, CAPE[1] School Functioning Assessment, SFA[1]
	(Subsections of) Other scales, Implicit measuring participation; not ABI specific Adaptive Behaviour Assessment System - Second Edition (ABAS-II) Child and Adolescent Scale of Environment, CASE[2] Child Behaviour Check List, CBCL (social competence scale)[1,2] Child Health Questionnaire, CHQ[1] Conflict Behaviour Questionnaire/Interaction Behaviour Questionnaire, CBQ/IBQ[2] Family Assessment Device, FAD[2] Family Burden of Injury Interview, FBII[2] Interpersonal Negotiation Strategies, INS[2] Mayo-Portland Adaptive Inventory-4, MPAI-4[2] Neuro-Quality of Life, Neuro-QOL (social relations)[2] Patient-Reported Outcomes Measurement Information System, PROMIS (peer relations)[2] Paediatric Evaluation of Disability Inventory, PEDI (social functioning scales)[2] Paediatric Quality of Life inventory, PedsQL (social subscale)[2] Social Skills Rating Scale, SSRS[2] Strengths and Difficulties Questionnaire, SDQ (peer relations and prosocial behaviour)[2] Video Social Inference Test, VSIT[2] Vineland Adaptive Behaviour Scale, VABS-II (socialization scale)[1,2]

[1] recommended participation measures by Bedell, et al, 2007; van Tol, et al, 2011

[2] recommended TBI outcome measures by Mc Cauley, et al, 2011

Appendix 3. Characteristics of 16 studies, using implicit participation outcome measures, with authors' suggestions on factors associated with participation after paediatric acquired brain injury.

First author, country	Study design	Year	Number of patients (TBI/ NTBI/controls)	Diag-nosis	Follow-up post injury in months (range)	Participation measure			Factors associated with participation[c]
						Explicit ABI[a]	Explicit general[a]	Implicit[b]	
Anderson, Australia	Prospective	2001	17 (17/0/35)	TBI	1-12-30	--	--	VABS-II	problems in communication
Janusz, USA	Prospective	2002	75 (75/0/46)	TBI	48 (36-60)	--	--	VABS-II, CBCL, INS	worse social information processing and problem solving
Stancin, USA	Prospective	2002	84 (84/0/50)	TBI	1-6-12-48 (36-60)	--	--	VABS-II, CHQ	worse adaptive skills; usage of medication
Hawley, United Kingdom	Retrospective	2004	67 (67/0/14)	TBI	24	--	--	VABS-II	problems in pre-injury behaviour and cognitive competences
Levin, USA	Cross-sectional	2004	58 (58/0/40)	TBI	36 (8-64)	--	--	VABS-II	location of injury; epilepsy
Yeates, USA	Prospective	2004	109 (109/0/80)	TBI	1-6-12-48 (36-60)	--	--	VABS-II, FAD, CBCL, INS	worse social information processing and problem solving ; problems in pre-injury behaviour and cognitive competences
Anderson, Australia	Prospective	2005	150 (150/0/0)	TBI	1-30	--	--	VABS-II , FBII	higher family burden; problems in pre-injury behaviour and cognitive competences
Aarsen, the Netherlands	Cross-sectional	2006	38 (0/38/0)	NTBI	91 (43-136)	--	--	PEDI, CBCL	presence of neurological comorbidities; worse adaptive skills; presence of mood problems
Anderson, Australia	Prospective	2006	84 (84/0/33)	TBI	1-6-30	--	--	PedsQL, FBII	problems in learning and applying knowledge, in pre-injury behaviour and cognitive competences; worse adaptive skills; higher family burden
Priagatano, USA	Retrospective	2006	60 (60/0/16)	TBI	16 (12-20)	--	--	CBCL	
Catroppa, Australia	Prospective	2008	48 (48/0/17)	TBI	1-6-30-60	--	--	VABS-II	problems in learning and applying knowledge; worse pre-injury family functioning
Levin, USA	Retrospective	2009	52 (52/0/41)	TBI	12	--	--	VABS-II	location of injury; epilepsy; problems in communication
Limond, United Kingdom	Cross-sectional	2009	47 (47/0/0)	TBI	34 (12-60)	--	--	PedsQL, SDQ	presence of mental fatigue
Muscara, Australia	Prospective	2009	36 (36/0/0)	TBI	104 (84-120)	--	--	ABAS-II	
Anderson, Australia	Cross-sectional	2009	124 (124/0/0)	TBI	163 (50-288)	--	--	VABS-II, ABAS-II, SSRS	
Kapapa, Germany	Prospective	2010	24 (24/0/0)	TBI	6-30	--	--	--	problems in daily living skills, in learning and applying knowledge; worse adaptive skills; presence of physical or mental fatigue
Rivara, USA	Prospective	2011	926 (729/0/197)	TBI	1-3-12-24	CASP		ABAS-II, PedsQL, CASE, FAD	

a according to Bedell, et al, 2007; van Tol, et al, 2011; b according to Bedell, et al, 2007; van Tol, et al, 2011; Mc Cauley, et al, 2011; c only factors additional to results in Table 2 are reported here; CASP=Child and Adolescent Scale of Participation; CAPE=Children's Assessment of Participation and Enjoyment ; ABAS II=Adaptive Behaviour Assessment System - Second Edition; CASE=Child and Adolescent Scale of Environment; CBCL=Child Behaviour Check List (social competence scale); CHQ=Child Health Questionnaire; FAD=Family Assessment Device; FBII=Family Burden of Injury Interview; INS=Interpersonal Negotiation Strategies; PEDI=Paediatric Evaluation of Disability Inventory (social functioning scale); PedsQL=Paediatric Quality of Life inventory (social subscale); SDQ=Strengths and Difficulties Questionnaire (peer relations and prosocial behaviour); SSRS= Social Skills Rating Scale, SSRS; VABS II=Vineland Adaptive Behaviour Scale Second Edition (socialization scale).

REFERENCES

1. Greenwald BD, Burnett DM, Miller MA. Congenital and acquired brain injury: Epidemiology and pathophysiology. Archives of Physical Medicine and Rehabilitation 2003;84:3-7.
2. CDC. National Center for Health Statistics. Health Data Interactive. 2009. Available online at: http://www.cdc.gov/nchs/hdi.htm. Accessed September 08, 2013.
3. Bedell GM, Dumas HM. Social participation of children and youth with acquired brain injuries discharged from inpatient rehabilitation: A follow-up study. Brain Injury 2004;18:65-82.
4. Trenchard SO, Rust S, Bunton P. A systematic review of psychosocial outcomes within 2 years of paediatric traumatic brain injury in a school-aged population. Brain Injury 2013;27:1217-1237.
5. Galvin J, Froude EH, McAleer J. Children's participation in home, school and community life after acquired brain injury. Australian Occupational Therapy Journal 2010;57:118-126.
6. Arroyos-Jurado E, Paulsen JS, Merrell KW, Lindgren SD, et al. Traumatic Brain Injury in School-Age Children Academic and Social Outcome. Journal of School Psychology 2000;38:571-587.
7. Hawley CA. Behavioural and school performance after brain injury. Brain Injury 2004;18:645-659.
8. Agnihotri S, Keightley ML, Colantonio A, Cameron D, et al. Community Integration interventions for youth with Acquired Brain Injuries: a review. Developmental Neurorehabilitation 2010;13:369-382.
9. Van Tol E, Gorter JW, DeMatteo C, Meester-Delver A. Participation outcomes for children with acquired brain injury: A narrative review. Brain Injury 2011;25:1279-1287.
10. Chevignard MP, Brooks N, Truelle JL. Community integration following severe childhood traumatic Brain injury. Current Opinion in Neurology 2010;23:695-700.
11. World Health Organization: International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY). Geneva, World Health Organization; 2007.
12. Bedell G, Coster W. Measuring participation of school-age children with traumatic brain injuries: Considerations and approaches. Journal of Head Trauma Rehabilitation 2008;23:220-229.
13. Rivara JB, Jaffe KM, Fay GC, Polissar NL, et al.Family functioning and injury severity as predictors of child functioning one year following traumatic brain injury. Archives of Physical Medicine and Rehabilitation 1993;74:1047-55.
14. Martin C, Falcone RA. Paediatric traumatic brain injury: an update of research to understand and improve outcomes. Current Opinions in Pediatrics 2008;20:294-299.
15. Poggi G, Liscio M, Adduci A, Galbiati S, et al. Psychological and adjustment problems due to acquired brain lesions in childhood: a comparison between post-traumatic patients and brain tumour survivors. Brain Injury 2005;19:777-785.
16. Taylor HG, Yeates KO, Wade SL, Drotar D, et al. Influences on first-year recovery from traumatic brain injury in children. Neuropsychology 1999;13:76-89.
17. Bedell G, Coster W, Law M, Liljenquist K, et al. Community participation, supports and barriers of school-age children with and without disabilities. Archives of Physical Medicine and Rehabilitation 2013;94:315-323.
18. PubMed Health. Bethesda (MD): National Library of Medicine (US). Available from: http://www.ncbi.nlm.nih.gov/pubmedhealth. Accessed November 12, 2012.
19. McCauley S, Wilde EA, Anderson VA, Bedell G, Beers SR, Campbell TF, et al. Recommendations for the Use of Common Outcome Measures in Pediatric Traumatic Brain Injury Research. Journal of Neurotrauma 2011;28:1-28.
20. Cieza A, Geyh S, Chatterji S, Kostanjsek N, et al. ICF Linking rules: an update based on lessons learned. Journal of Rehabilitation Medicine 2005;37:212-218.
21. Schouffoer AA, Schoones JW, Terwee CB, Vliet Vlieland TPM. Work status and its determinants among patients with systemic sclerosis: a systematic review. Rheumatology 2012;51:1304-1314.
22. Shamliyan T, Kane RL, Dickinson S. A systematic review of tools used to assess the quality of observational studies that examine incidence or prevalence and risk factors for diseases. Journal of Clinical Epidemiology 2010;63:1061-1070.
23. Hayden JA, Cote P, Bombardier C. Evaluation of the quality of prognosis studies in systematic reviews. Annals of Internal Medicine 2006;144:427-437.
24. Katz-Leurer M, Rotem H, Keren O, Meyer S. Recreational physical activities among children with a history of severe traumatic brain injury. Brain Injury 2010;24:1561-1567.
25. Rivara FP, Vavilala MS, Durbin D, Temkin N, et al. Persistence of disability 24 to 36 months after pediatric traumatic brain injury: a cohort study. Journal of Neurotrauma 2012;29:2499-2504.
26. Bedell GM, Dumas HM. Social participation of children and youth with acquired brain injuries discharged from inpatient rehabilitation: a follow-up study. Brain Injury 2004;18:65-82.
27. Yeates KO, Swift E, Taylor G, Wade S, et al. Short- and long-term social outcomes following pediatric traumatic brain injury. Journal of the International Neuropsychological Society 2004;10,412-426.
28. Janusz JA, Kirkwood MW, Yeates KO, Taylor HG. Social problem-solving skills in children with traumatic brain injury: longterm outcomes and prediction of social competence. Child Neuropsychology 2002;8:179-194.
29. Anaby D, Law M, Hanna S, Dematteo C. Predictors of change in participation rates following acquired brain injury: results of a longitudinal study. Developmental Medicine and Child Neurology 2012;54:339-346.

30. Levin HS, Hanten G, Li X. The relation of cognitive control to social outcome after paediatric TBI: Implications for intervention. Developmental Neurorehabilitation 2009;12:320-329.
31. Levin HS, Zhang L, Dennis M, Ewing-Cobbs L, et al. Psychosocial outcome of TBI in children with unilateral frontal lesions. Journal of International Neuropsychological Society 2004;10:305-316.
32. Galvin J, Froude EH, McAleer J. Children's participation in home, school and community life after acquired brain injury. Australian Occupational Therapy Journal 2010;57:118-126.
33. Anderson V, Brown S, Newitt H, Hoile H. Educational, vocational, psychosocial, and quality-of-life outcomes for adult survivors of childhood traumatic brain injury. Journal of Head Trauma Rehabilitation 2009;24:303-12.
34. Anderson VA, Catroppa C, Dudgeon P, Morse SA, et al. Understanding predictors of functional recovery and outcome 30 months following early childhood head injury. Neuropsychology 2006;20:42-57.
35. Catroppa C, Anderson VA, Morse SA, Haritou F, et al. Outcome and predictors of functional recovery 5 years following pediatric traumatic brain injury (TBI). Journal of Pediatric Psychology 2008;33:707-718.
36. Anderson VA, Catroppa C, Haritou F, Morse S, et al. Identifying factors contributing to child and family outcome 30 months after traumatic brain injury in children. Journal of Neurology, Neurosurgery, and Psychiatry 2005;76:401-408.
37. Anderson V, Catroppa C, Morse S, Haritou F, et al. Outcome from mild head injury in young children: A prospective study. Journal of Clinical and Experimental Neuropsychology 2001;23:705-717.
38. Limond J, Dorris L, McMillan TM. Quality of life in children with acquired brain injury: parent perspectives 1-5 years after injury. Brain Injury 2009;23:617-622.
39. Horneman G, Folkesson P, Sintonen H, von Windt L, et al. Health-related quality of life of adolescents and young adults 10 years after serious traumatic brain injury. International Journal of Rehabilitation Research 2005;28:245-249.
40. Kapapa T, Pfister U, Konig K, Sasse M, et al. Head trauma in children, part 3: clinical and psychosocial outcome after head trauma in children. Journal of Child Neurology 2010;25:409-422.
41. Wells R, Minnes P, Phillips M. Predicting social and functional outcomes for individuals sustaining paediatric traumatic brain injury. Developmental Neurorehabilitation 2009;12:12-23.
42. Rivara FP, Koepsell TD, Wang J, Temkin N, et al. Disability 3, 12, and 24 months after traumatic brain injury among children and adolescents. Pediatrics 2011;128:1129-1138.
43. Stancin T, Drotar D, Taylor HG, Yeates KO, et al. Health-related quality of life of children and adolescents after traumatic brain injury. Pediatrics 2002;109:E34.
44. Hawley CA. Behaviour and school performance after brain injury. Brain Injury 2004;18:645-659.
45. Aarsen FK, Paquier PF, Reddingius RE, Streng IC, Arts WFM, Evera-Preesman M, et al. Functional outcome after Low-Grade Astrocytoma treatment in childhood. Cancer 2006;106:396-402.
46. Muscara F, Catroppa C, Eren S, Anderson V. The impact of injury severity on long-term social outcome following paediatric traumatic brain injury. Neuropsychological Rehabilitation 2009;19:541-561.
47. Prigatano GP, Gupta S. Friends after traumatic brain injury in children. Journal of Head Trauma Rehabilitation 2006;21:505-513.
48. Imms C. Children with cerebral palsy participate: a review of the literature. Disability and Rehabilitation 2008;30:1867-1884.
49. Bult MK, Verschuren O, Jongmans MJ, Lindeman E, et al. What influences participation in leisure activities of children and youth with physical disabilities? A systematic review. Research in Developmental Disabilities 2011;32:1521-1529.
50. Shikako-Thomas K, Majnemer A, Law M, Lach L. Determinants of participation in leisure time of children and youth with cerebral palsy: a systematic review. Physical and Occupational Therapy in Pediatrics 2008;28:155-169.
51. King G, Law M, King S, Rosenbaum P, et al. A conceptual model of factors affecting the recreational and leisure participation of children with disabilities. Physical and Occupational Therapy in Pediatrics 2003;23:63-90.
52. Law M, King G, King S, Kertoy M, et al. Patterns of participation in recreational and leisure activities among children with complex physical disabilities. Developmental Medicine and Child Neurology 2006;48:337-342.
53. McDougall J, Bedell G, Wright V. The youth report version of the Child and Adolescent Scale of Participation (CASP): Assessment of psychometric properties and comparison with parent report. Child: Care, Health and Development 2013;39:512-522.
54. Coster W, Bedell G, Law M, Khetani MA, et al. Psychometric evaluation of the Participation and Environment Measure for Children and Youth. Developmental Medicine and Child Neurology 2011;53:1030-1037.
55. Steiner WA, Ryser L, Huber E, Uebelhart D, et al. Use of he ICF Model as a Clinical Problem Solving Tool in Physical Therapy and Rehabilitation Medicine. Physical Therapy 2002;82:1098-1107.
56. Coster W, Khetani MA. Measuring participation of children with disabilities: Issues and challenges. Disability and Rehabilitation 2008,30:639-648.
57. Whiteneck G, Dijkers MP. Difficult to measure constructs: conceptual and methodological issues concerning participation and environmental factors. Archives of Physical Medicine and Rehabilitation 2009;90 (Suppl 1), S22-S35.