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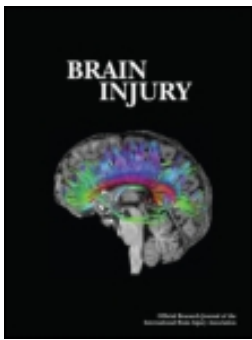
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REVIEW ARTICLE

Determinants of participation of youth with acquired brain injury: A systematic review

Arend J. de Kloet^{1,2}, Rianne Gijzen³, Lucia W. Braga⁴, Jorit J. L. Meesters^{1,5}, Jan W. Schoones⁵, & Thea P. M. Vliet Vlieland^{1,5}

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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–November 2014 was performed. All clinical studies describing determinants of participation at least 1 year after the diagnosis of ABI by means of one or more pre-defined 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: Eight studies using an explicit participation outcome measure were selected after review, including a total of 1863 patients, with a follow-up ranging from 1 up to 288 months. Three studies included patients with a traumatic or a non-traumatic brain injury (TBI or NTBI) and five studies with only TBI patients. Factors consistently found to be associated with more participation restrictions were: greater severity of ABI, impaired motor, cognitive, behavioural and/or sensory functioning, limited accessibility of the physical environment and worse family functioning. Fewer participation problems were associated with a supportive/nurturing parenting style, higher household income, acceptance and support in the community and availability of special programmes. The overall methodological quality of the included studies was high in two and moderate in six studies.

Conclusion: This systematic review shows that only a few, moderate quality, studies on the determinants of participation after paediatric ABI using recommended explicit measurement instruments are available. Various components of the ICF model: 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.

Keywords

Community integration, outcome, paediatric, social reintegration, stroke, traumatic brain injury

History

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Introduction

Acquired brain injury (ABI) refers to any damage to the brain that occurs after birth [1] and may have a traumatic (traumatic brain injury, TBI) or non-traumatic cause (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 limitations in functioning [3–10].

So far, studies on the outcome of ABI 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].

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Regarding the extent and nature of participation restrictions, few literature reviews on participation outcomes after paediatric ABI are available; one review on behavioural outcome and adaptive functioning [4], one on community integration interventions [8] and two narrative reviews on participation outcome measures [9, 10] are available. Overall, it was found that children and adolescents with ABI had significantly more 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 1 year or less [4, 8–10]. Up until now, literature on the determinants of participation after paediatric ABI have not been systematically summarized. In a number of studies addressing participation 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, programmes/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 co-operation 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 4 November 2014.

Data collection and analysis

Four steps were defined 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 over the selection or data extraction, consensus was reached through discussion. If consensus between the three authors was not achieved, a final decision was made by a fourth 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 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 studies where adult patients were also included, the study 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 above-mentioned criteria were used again. 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, 20] and (5) using the results of at least one recommended explicit outcome measure as a dependent variable in the data analysis.

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 above-mentioned 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 characteristics registered were: the number of subjects in the study, diagnosis, inclusion

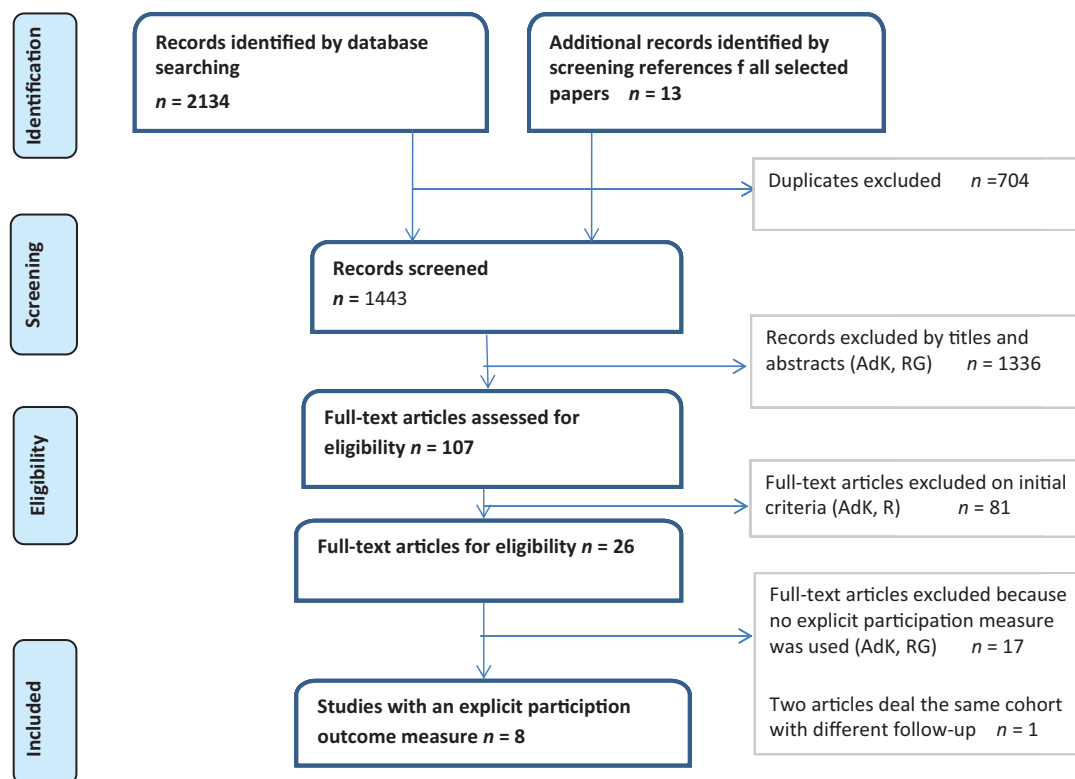


Figure 1. Flow chart.

criteria, time since onset of ABI and socio-demographic characteristics (age, sex) were registered.

For the participation outcome, the time of the follow-up assessment and the instruments used to measure participation were noted [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 [21] 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 the results of association analyses 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 one 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, this study used a quality checklist employed in similar reviews

but in other patient groups, 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 a question mark and scored as ‘bias or unclear’. Bias was considered present if more than two 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 three categories, moderate with bias in one or two and low with bias in all three categories.

Results

Figure 1 presents the selection of studies. The initial electronic database search yielded 2134 records, from which 13 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 three 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.

Nine papers meeting all inclusion criteria were selected. Two of these nine 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, so that eight studies were finally included [25, 26, 29, 32, 33, 41, 43, 46].

Study characteristics

The characteristics of the eight included studies [25, 26, 29, 32, 33, 41, 43, 46] are presented in Table I. Five studies [26, 29, 41, 42, 43] were from the North Americas, whereas three [32, 33, 46] were executed in Australia. Four studies had a cross-sectional design [26, 32, 33, 41], the other four studies had a prospective design [29, 42, 43, 46]. Five studies [33, 41, 42, 43, 46] were concerned with TBI only, whereas the other three studies [26, 29, 32] included both patients with TBI and NTBI. Eight different age ranges were used in eight studies, varying in length from 12–19 years. Three studies [33, 42, 43] included children under the age of 4, whereas six studies included patients up to at least 18 years old. The number of (follow-up) measurements varied from one to five, the time since the onset of injury ranged from 1–288 months in all eight studies. In two of the four prospective studies [42, 43], 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 I the measurement instruments employed in the eight selected studies are presented. The explicit participation measures included the Child and Adolescent Scale of Participation (CASP) [26, 32, 41–43], the Children's Assessment of Participation and Enjoyment (CAPE) [29] and the Sydney Psychosocial Reintegration Scale for Children (SPRS-C) [33, 46].

Two of the three cross-sectional studies, both using the CASP, found that, depending on the age group, 30–73% [26] and 25–75% [32] of children and youth were restricted in at least one participation domain (at home, at school or in community).

In another cross-sectional study, 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). All patients were missing adequate support and attitudes in environment [41]. Mobility or moving around was least restricted in and around the home (30%), more problems were experienced in moving around in community (55%) [26, 32, 41].

With respect to the prospective studies, Rivara et al. [25, 42], using the CASP, found significantly worse total participation scores at all four time points compared to a control group with an arm injury. Anaby et al. [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

Table I. Characteristics of eight studies (nine papers), using explicit participation outcome measures, on determinants of participation after paediatric acquired brain injury.

Reference, 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 and Dumas [26], USA	Cross-sectional	2004	60 (38/22/0)	TBI + NTBI	42 (4–80)	CASP		PEDI, CASE
Wells et al. [41], Canada	Cross-sectional	2009	30 (30/0/0)	TBI	30 (12–60)	CASP		CASE
Anderson et al. [33], Australia	Cross-sectional	2009	124 (124/0/0)	TBI	163 (50–288)	SPRS-C		ABAS-II, SPST-R, SSRS
Muscara et al. [46], Australia	Prospective	2009	36 (36/0/0)	TBI	104 (84–120)	SPRS-C		CASE
Galvin et al. [32], Australia	Cross-sectional	2010	20 (12/8/0)	TBI + NTBI	25 (4–84)	CASP		ABAS-II, PedsQL, CASE, FAD
Rivara et al. [25, 42], USA	Prospective	2012	926 (729/0/19)	TBI	1, 3, 12, 24, 36	CASP	CAPE	FAD, CASE
Anaby et al. [29], Canada	Prospective	2012	136 (113/23/0)	TBI + NTBI	8, 12			ABAS-II
Jimenez et al. [43], USA	Prospective	2013	531 (531/0/0)	TBI	3, 12, 24, 36	CASP		

^aAccording to Bedell et al. [3]; van Tol et al. [9]; Soo et al. [40].

^bAccording to Bedell et al. [3]; van Tol et al. [9]; McCauley et al. [19].

CASP, Child and Adolescent Scale of Participation; CAPE, Children's Assessment of Participation and Enjoyment; SPRS, Sydney Psychosocial Reintegration Scale for Children (SPRS-C); 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 sub-scale).

Table II. Results of eight studies on determinants of participation of children and youth with acquired brain injury.

Health condition ^a	Independent variables			
	Body functions and structure ^a	Activities ^a	Environmental factors ^a	Personal factors ^a
Greater severity of ABI –: 29*, 33*, 41*, 42*, 46*	<i>Mental functions^b</i> (b140–b189 ^c) Problems in cognitive functioning ^d –: 26*, 32 Problems in behavioural functioning –: 26*, 32 Problems in emotional functioning –: 26* Problems in social problem-solving –: 46*	<i>General tasks/routines</i> (d210–d299) Capacity +: 32	<i>Physical environment</i> (e210–e299) Problems in accessibility, design –: 26*, 32, 41*	General health problems –: 26*
Type/cause of injury =: 26*, 29*, 32	<i>Sensory functions and pain</i> (b210–b229) Sensory functioning problems –: 26*, 32	<i>Mobility</i> (d410–499) Capacity +: 32; =: 26*	<i>Support and relations</i> (e310–e399) Worse family functioning –: 29*, 43; =: 42* Supportive nurturing and parenting style +: 32, 41* Higher household income (social economic status) +: 29*, 33*, 42*, 46* Higher parental education +: 44; =: 42*	Younger age (at onset) –: 41* Longer time since onset –: 29*; =: 26*, 32 Older age (at follow-up) –: 42*
Presence of neurological comorbidities =: 42*	<i>Voice and speech</i> (b310–b399) Speech problems –: 26* <i>Movement-related functions</i> (b710–b729) Problems in movement functions –: 26*, 32	<i>Self-care</i> (d510–599) Capacity +: 26*	<i>Attitudes</i> (e410–499) Acceptance and support in community +: 26*, 32, 41* <i>Services, systems policy</i> (e510–599) Availability of special programmes +: 26*, 32, 41* Availability of special services +: 26*, 32, 41* Length of stay in inpatient rehabilitation =: 26*	Race/Ethnicity –: 43; =: 26* Problems in pre-injury adaptive functioning –: 46*

*multivariate analysis.

According to the ICF-CY: ^acomponent; ^bchapter; ^ccode; ^dcategory.

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.

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. Jimenez et al. [43] studied differences between Hispanic and non-Hispanic white children with TBI resulting in a worse participation outcome for the Hispanic children. Muscara et al. [46] investigated the long-term social outcome following the transition into adulthood and found significant group differences between mild and moderate–severe TBI groups on self- and parent-rated social reintegration and self-rated interpersonal relationship, work and leisure domains.

Determinants of participation

Table II 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, SPRS-C), at school (CASP, SPRS-C) and in the community (CASP, CAPE, SPRS-C), as well as participation at school or work (CASP, SPRS-C) and structured events in community, social and civic life (CASP, CAPE, SPRS-C). Six studies [26, 29, 33, 41, 42, 46] employed multivariate analyses.

The factor which was 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.

In the ICP component Body Functions and Body Structures, problems in movement functions, cognitive

Table III. Quality assessment of eight 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
Anderson, Australia [33]	1	0	0	0/3	H
Muscara, Australia [46]	0	0	0	0/3	H
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
Jimenez, USA [43]	0	0	1	1/3	M

^a0 = no bias present; 1 = bias present or unclear.

^bH = 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.

functioning, behavioural functioning and sensory functioning were significantly associated with more participation restrictions. Regarding the component Environmental Factors, problems in accessibility and design of the physical environment and worse family functioning 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 programmes 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.

Methodological quality of studies

Table III summarizes the results of the methodological quality assessment of the eight included studies. The methodological quality was rated as high in two and moderate in six studies, mainly due to selection bias.

Discussion

In this systematic review, eight studies on determinants of participation of children and adolescents after ABI were included, with five studies only including patients with TBI and two studies being of high and six of moderate methodological quality.

These eight studies showed that, 12–288 months after the onset of ABI, 25–80% of children and youth were restricted in at least one 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 this 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, 47], 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 one or several domains of participation.

The factors most consistently associated with participation restrictions 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, worse family functioning, higher social economic status and availability of special services in programmes (Environmental Factors). No consistently associated factors were found in the ICF categories Activities and Personal Factors.

The results concerning the determinants of more participation restrictions after paediatric ABI are comparable with the literature with respect to 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] and restrictions in physical, social and attitudinal environment [17]. Longer time since onset [7] was found to be a determinant of participation in some 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 or problems in mobility [2] on participation after paediatric ABI.

In addition to the results from previous syntheses of the literature, this review showed a number of new relevant factors, e.g. problems in sensory functioning and acceptance and support in community.

Problems in speech, emotional functioning, problem-solving skills, capacity in general tasks and self-care, general health and pre-injury adaptive functioning as well as younger age (at onset) and older age (at assessment) were found to be associated factors in one study with a multivariable analysis.

It should be noted that the included eight studies differed considerably regarding their focus on specific participation domains (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.

In six out of eight studies the methodological quality of the studies was moderate, due to potential bias in all three aspects of the instrument which was applied: five studies showed selection bias (specifically lack of theoretical background or

loss of patients in follow-up) and two presented statistical analysis bias (specifically missing information on missing values). Included studies showed a great variety in independent variables, e.g. age at inclusion, age range, time since onset of injury and number of (follow-up) measurements. It should be noted that some of the studies in this 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, these findings can only be compared with similar syntheses of the literature concerning children with other conditions, such as Cerebral Palsy (CP) [48–50] and other physical limitations [51, 52]. In these studies participation was found to be associated with a variety of factors as well. Gender, 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). Unlike 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, one 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. This review 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 and selection of instruments.

Another limitation is the limited number of eight included studies. In the search strategy, only studies published in English were included, so 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. Third, only a small sample of children and adolescents with NTBI was included in the three selected papers, while determinants of participation outcome after TBI cannot be generalized across various aetiologies of NTBI [58]. Finally, all studies were performed in Western countries, five in the North Americas and three in Australia; this limits broader generalization of results as well.

Therefore, international consensus is recommended 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, two

explicit participation outcome measures have been developed as explicit participation outcome measures 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 [55–57]. The ICF model serves to under-score the complexity, inter-related 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) is arbitrary. Moreover, the distinction between general (d710–729) vs complex (d720–729) vs special (d730–779) interpersonal interactions is arbitrary. Some categories require specification regarding paediatric ABI, e.g. in external factors (ICF code e) and family (e310), which 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.

Although this review found several factors to be associated with participation, the diversity of both potential determinants and outcome measures used in the various studies does allow the construction of a comprehensive multifactorial model for participation in ABI. The development of such a model is also hindered by the observation that a clear definition of participation is not provided by the ICF and it is criticized for not being comprehensive [59], logical or distinctive [60] regarding participation.

In this review, three studies included patients with TBI and NTBI and five studies only patients with TBI.

As these studies focused on different potential determinants of participation (and also varied regarding the use of the pre-defined explicit outcome measures) it is difficult to draw any conclusions on potential differences in the factors associated with participation in these two groups.

Further research is suggested with respect to participation of children and youth with ABI, to decrease the current knowledge gap regarding participation outcomes. This will facilitate the evaluation of rehabilitation programmes with respect to participation outcome, including generalizability in everyday life. A pre-requisite for such research is that consensus regarding the definition of participation, the usage of recommended, explicit participation outcome measures and the set of potential determinants to be analysed is attained. Moreover, studies should include large cohorts of children and youth in all age groups and different causes and

severity of the injury (TBI and NTBI) and should employ a methodologically sound analysis, in particular the use of multivariate statistical analyses.

Moreover, the contents of currently recommended explicit participation of outcome measures needs further refinement. Preferably, they should be developed according to guidelines regarding the development of participation measures, including:

- (a) Definition of the aim of measuring: description (e.g. activities, time, patterns, limitations), discrimination (differences between groups) or evaluation (change over time) (Bedell, 2014);
- (b) Employing mixed methods research, combining quantitative and qualitative data [9]; and
- (c) Inclusion of environmental factors, differentiation regarding sub-domains with specific aspects of participation (e.g. social interactions at work) and differentiation regarding age (e.g. play of younger children) [61].

Conclusion

In this systematic review on determinants of participation after paediatric ABI, eight studies using an explicit participation outcome measure were included, two of a high and six of a moderate methodological 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

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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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 Haemorrhage' OR 'Traumatic Brain Stem Haemorrhage' OR 'Traumatic Cerebral Haemorrhage' OR 'Traumatic Brain Haemorrhages' OR 'Traumatic Cerebral Haemorrhages' 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 children and youth with acquired brain injury.

Dependent (outcome) variables	<i>Explicit participation measures; ABI-specific</i> Child and Adolescent Scale of Participation, CASP^{a,b} Sydney Psychosocial Reintegration Scale for Children, SPRS-C^c <i>Explicit participation measures; not ABI-specific</i> Assessment of Life Habits for Children, LIFE-H^a Children's Assessment of Participation and Enjoyment, CAPE^a School Functioning Assessment, SFA^a <i>(Sub-sections of) Other scales, Implicit measuring participation; not ABI-specific</i> Adaptive Behaviour Assessment System–Second Edition (ABAS-II) Child and Adolescent Scale of Environment, CASE^b Child Behaviour Check List, CBCL (social competence scale)^{a,b} Child Health Questionnaire, CHQ^a Conflict Behaviour Questionnaire/Interaction Behaviour Questionnaire, CBQ/IBQ^b Family Assessment Device, FAD^b Family Burden of Injury Interview, FBII^b Interpersonal Negotiation Strategies, INS^b Mayo-Portland Adaptive Inventory-4, MPAL-4^b Neuro-Quality of Life, Neuro-QoL (social relations)^b Patient-Reported Outcomes Measurement Information System, PROMIS (peer relations)^b Paediatric Evaluation of Disability Inventory, PEDI (social functioning scales)^b Paediatric Quality-of-Life inventory, PedsQL (social sub-scale)^b Social Skills Rating Scale, SSRS^b Strengths and Difficulties Questionnaire, SDQ (peer relations and pro social behaviour)^b Video Social Inference Test, VSIT^b Vineland Adaptive Behaviour Scale, VABS-II (socialization scale)^{a,b}
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^arecommended participation measures by Bedell et al. [3]; van Tol et al. [9].

^brecommended TBI outcome measures by McCauley et al. [19].

^crecommended participation measure by Tate et al. [20].

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)	Diagnosis	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

(continued)

First author, country	Study design	Year	Number of patients (TBI/NTBI/ controls)	Diagnosis	Follow-up post-injury in months (range)	Participation measure			Factors associated with participation ^c
						Explicit ABI ^a	Explicit general ^a	Implicit ^b	
Hawley, UK	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, UK	Cross-sectional	2009	47 (47/0/0)	TBI	34 (12–60)	–	–	PedsQL, SDQ	Presence of mental fatigue
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	
Rosema, Australia	Prospective	2013	33 (33/0/0)	TBI	200 (176–224)	–	–	VABS-II, ABAS-II	Problems in pre-injury behaviour competences

^aAccording to Bedell et al. [3]; van Tol et al. [9].

^bAccording to Bedell et al. [3]; van Tol et al. [9]; McCauley et al. [19].

^cOnly factors additional to results in Table II 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 pro-social behaviour); SSRS, Social Skills Rating Scale; VABS II, Vineland Adaptive Behaviour Scale Second Edition (socialization scale).