

SYSTEMATIC REVIEW

Strategies supporting parent-delivered rehabilitation exercises to improve motor function after paediatric traumatic brain injury: A systematic review

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Abstract

Aim: To identify and analyse ways in which parents are supported to deliver rehabilitation exercises to their child after traumatic brain injury (TBI), conceptualized as strategies.

Method: A systematic search was completed using seven online databases and three grey literature databases, from inception to November 2021. The included studies focused on physical rehabilitation in children after TBI with the involvement of parents as hands-on deliverers or facilitators of rehabilitation (e.g. supervising the exercise). Intervention descriptions were reviewed to identify strategies; this was followed by fine-grained analysis using the Behaviour Change Wheel to identify intervention components. Risk of bias was analysed using the revised Cochrane Risk-of-Bias Tool for Randomized Trials or the Risk Of Bias In Non-randomized Studies - of Interventions.

Results: Six interventions including 211 participants and one trial protocol met the inclusion criteria. All studies included a proportion of children diagnosed with TBI and four studies included mixed samples of acquired brain injury or cerebral palsy. All interventions included elements of goal setting and instruction.

Interpretation: Interventions focus heavily on the initiation of physical rehabilitation, but focus less on the longer-term maintenance of rehabilitation delivery. Further research should integrate perspectives from parents to inform the development of new interventions.

Traumatic brain injury (TBI) is a form of acquired brain injury that occurs when a sudden external force causes damage to the brain.¹ TBI is a leading cause of death and long-term disability in children worldwide,²⁻⁶ estimated to result in the hospitalization of 74 children per 100 000 annually.⁵ TBI can affect the physical, social, emotional, and psychological functions of the individual involved,⁷ having significant implications not only for the child but also their entire family.⁸⁻¹⁰ Such is the impact of TBI on the family that it has been referred to as a 'family affair'.¹¹

After hospitalization with TBI, many children will continue to experience physical impairments and require intensive and, in some cases, long-term neurorehabilitation to support improvements and maintenance of motor function, including gross and fine motor function.^{12,13} Motor function is used in this context because it encompasses all aspects of movement, including the purely physical components of movement plus the perceptual and cognitive elements.¹⁴

The impact of TBI on function can be conceptualized using the common language of the International Classification of

Abbreviations: BCT, behaviour change technique; BCTTv1, Behaviour Change Technique Taxonomy v1; COM-B, Capabilities, Opportunities, and Motivation - Behaviour model; RoB 2, revised Cochrane Risk-of-Bias Tool for Randomized Trials; ROBINS-I, Risk Of Bias In Non-randomized Studies - of Interventions; TBI, traumatic brain injury.

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Functioning, Disability and Health for Children and Youth.¹⁵ This framework considers functioning according to the structures and functions of the body, activity limitations, and participation while also considering the impact of an individual's personal and environmental factors. Rehabilitation exercises aim to improve and maintain motor function; this requires intense repetition of specific activities that are important to support the process of neuroplasticity.¹⁶ Neuroplasticity is the ability of the brain to adapt and reorganize neural networks in response to environmental stimuli, experiences, and challenges;¹⁷ work is ongoing to understand more about the dose-response relationships within rehabilitation.^{18,19}

Family-centred care after paediatric traumatic brain injury

Evidence demonstrates that the outcomes for children and families are reciprocal and bidirectional.²⁰ It is for this reason that support for the child and their family is so important, with patient-centred and family-centred care widely considered as best practice.²¹ Where families have been supported to deliver rehabilitation exercises, it is often parents that are supported.^{10,12}

It is the role of health care professionals, such as physiotherapists and occupational therapists, to empower parents and legal guardians (hereon referred to as 'parents') to be able to continue their child's rehabilitation exercises at home with support from community services so that the transition to home is safe and with the aim of improving long-term outcomes.²² This type of support is complex and multifaceted, involving elements of behavioural change on the part of parents to learn, prioritize, and follow relevant recommendations from health care professionals.²³⁻²⁵

While family-centred care and the involvement of parents has long been considered an important element of rehabilitation,^{10,26,27} little is known about how parents are actually supported to deliver rehabilitation exercises. This is an important consideration, emphasized by the fact that behavioural change and parent-supported rehabilitation are among the James Lind Alliance top 10 research priorities within physiotherapy.²⁸ To shed light on how parents are supported to deliver rehabilitation, an approach is required to move beyond descriptions of interventions to understand their component parts. We propose that behavioural change theory and frameworks provide an appropriate method for doing this.

Importance of behaviour change to support the delivery of rehabilitation at home

To enhance our understanding of how interventions can achieve behaviour change, analysis beyond the basic description of their delivery is required. To understand the active ingredients of interventions (e.g. goal setting) and identify promising strategies for future interventions, Michie et al.²⁹ developed the Behaviour Change Technique Taxonomy v1 (BCTTv1). A behaviour change technique

What this paper adds

- Parents need support to deliver or supervise rehabilitation exercises.
- The interventions identified in this review supported goal setting, action planning, and learning rehabilitation exercises.
- Interventions focused primarily on the initiation of exercises but less on maintenance.
- Rehabilitation is complex and new approaches are needed to better support parents.

(BCT) is an 'observable, replicable, and irreducible component of an intervention'.²⁹ Furthermore, the Behaviour Change Wheel³⁰ provides a complementary framework to unpack complex, multifaceted interventions, supporting parents in delivering rehabilitation to their child. Interventions can be characterized in terms of intervention functions, that is, broad categories of means through which behaviour change may be achieved (e.g. education). Finally, in terms of the respective targets of the interventions and their mechanisms of action, the Capabilities, Opportunities, and Motivation - Behaviour (COM-B) model³⁰ and Theory and Techniques Tool^{31,32} can be used to aid understanding.

This systematic review aimed to identify existing interventions designed to support parents to deliver rehabilitation exercises aimed at improving the motor function of their child after a TBI. The means by which support for parents is delivered, conceptualized as strategies, was identified from the description of interventions, followed by a fine-grained analysis of component BCTs, intervention functions, and mechanisms of action.

METHOD

This systematic review was carried out in accordance with the protocol published with PROSPERO (no. CRD42021290183). This review has been reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.³³

Inclusion criteria

Study type

Studies were included if they were published in peer-reviewed journals and met the inclusion criteria, regardless of the language they were written in. For non-English studies, support was sought for translation from colleagues with appropriate expertise in the field who were fluent in the required language to enable translation and assess eligibility of the

study against the inclusion criteria. Published, unpublished (e.g. doctoral theses), and grey literature using quantitative, qualitative, or mixed methods approaches were included. This included studies describing intervention development or evaluation of interventions through randomized controlled trials, pilot or feasibility studies, or observational studies. Study protocols were included if they met the inclusion criteria.

Participant and population inclusion criteria

Participants were the parents of children (younger than 18 years at the time of their injury) with a diagnosis of TBI. Studies where the child with TBI was the recipient of the intervention were included, provided that explicit reference was made to parent involvement in the description of the participants or the intervention. Studies that included no reference to parents were excluded.

Studies describing patient groups other than TBI (e.g. those affected by an acquired brain injury) were included if they made explicit reference to the inclusion of participants with TBI. Studies that made no reference to TBI were excluded.

Interventions

The studies included in this review reported interventions that referred to the delivery of rehabilitation exercises aimed at improving the motor function (including physical function) of children after a TBI. The interventions included could additionally target other areas of human functioning (e.g. cognitive function), provided that the intervention also explicitly targeted motor function.

Outcomes

The main outcome of interest was the motor function of children, including gross and fine motor function. Intervention development work and feasibility studies did not need to make explicit reference to outcomes.

Search strategy

An in-depth systematic search strategy was developed according to the patient/population, intervention, comparison, and outcomes criteria, in consultation with the review team and a specialist librarian (Appendix S1).

Online database search

One author (DY) conducted systematic searches using seven online databases, including MEDLINE, Allied and

Complementary Medicine, Cumulative Index to Nursing and Allied Health Literature, PsycINFO, Embase, Scopus, and the Cochrane Library, including the Cochrane Central Register of Controlled Trials, from inception to 2nd November 2021. Searches were conducted with no geographical location or language restriction.

Search terms consisted of different variations of keywords, including combinations of (1) population (child* OR teen* OR youth) AND (mother* OR father* OR parent* OR famil*); (2) intervention (physiotherp* OR physical therap* OR PT OR occupational therapist OR OT); and (3) outcome (motor* OR movement* OR physical function*). There was no requirement for studies to include a control group. Keywords were combined using Boolean logic (AND, OR, NOT); advanced search techniques, such as Medical Subject Headings, were used where relevant. For the search strategies employed in each database, see Appendix S2.

Grey literature searches

One author (DY) conducted systematic searches in three grey literature databases, including Ethos, Open Grey, and ProQuest from inception to 26th November 2021. Search terms were based around the patient/population, intervention, comparison, and outcomes criteria as outlined earlier and modified for each database.

Identification of studies

All identified studies were exported to EndNote X9 (Clarivate, Philadelphia, PA, USA) and deduplicated. Titles and abstracts were reviewed against the inclusion criteria by the lead author (DY); a random sample of 20% of studies was double-screened by a second reviewer (SC) at the title and abstract screening phase.³⁴ Interrater reliability of paper selection using Cohen's kappa was calculated.³⁵

The full texts of the studies retained were downloaded and screened by the lead author (DY), with a random sample of 20% double-screened by a second reviewer (SC). Interrater reliability was again assessed using Cohen's kappa.³⁵ The reasons for the exclusion of studies at the full-text screening phase are reported in the PRISMA flow diagram (Figure S1). A third reviewer (WH) was on hand to facilitate discussion about disagreements between reviewers.

Theses identified from the grey literature searches were screened for eligibility by the lead author (DY) at the title, abstract, and full-text screening phases.

Data extraction

The primary purpose of this review was to identify strategies used to support parents to deliver rehabilitation exercises, which informed the data extraction and synthesis processes.

Data extraction also included numerical data related to the effectiveness of interventions; however, this was not the primary purpose of the review.

Data extraction was completed by the lead author using a custom-made data extraction template, with the extracted data relating to intervention descriptions and strategies checked for accuracy by two other reviewers (KM and WH). The template was developed in agreement with the review team and piloted with one of the studies included before use with all studies included in the review. Extracted data included general content, such as study title, lead author's name, country, year, and journal name; study characteristics, such as design, number of groups, study aims, recruitment method, and number of participants; and participant baseline characteristics, such as age, sex, ethnicity, and type of injury. Outcome measures and study outcomes using numerical data were also extracted, although this was not the primary purpose of the review.

Identification of intervention content

Intervention descriptions from the studies included were independently reviewed by two reviewers (DY and KM) to identify strategies. Where a protocol was accepted alongside a published study, data were extracted from both. Identified strategies were discussed; where discrepancies existed, a third reviewer (WH) supported discussion until agreement was reached.

Intervention strategies were reviewed and component BCTs were independently coded by two reviewers (DY and WH) using the BCTTv1.²⁹ The BCTTv1 is a taxonomy of 93 hierarchically structured BCTs divided into 16 groups through expert consensus, which is applied extensively within behavioural science.²⁹ The lead author and first coder (DY) completed the accredited online BCT training course;³⁶ the second coder coauthored the BCTTv1 (WH).²⁹ BCTs were coded each time they appeared in the intervention and control conditions to provide insight into both their presence and intensity. Coders additionally assigned the level of certainty with which each BCT was present: a '+' symbol was assigned when the BCT was thought to be present in all probability; '++' was assigned when the BCT was deemed present beyond all reasonable doubt. The two coders discussed any discrepancies until agreement was reached.

Subsequently, for each BCT, all the corresponding intervention function(s) were coded using Table 3.3 of the Behaviour Change Wheel book.³⁰ Reviewers did not make judgements about the relevance of each intervention function to the BCT. They also coded relevant mechanism(s) of action using the Theory and Techniques Tool,³¹ a tool that triangulates evidence from published literature and expert consensus of 26 mechanisms of action with 74 BCTs. Finally, Tables 2.2 and 2.3 of the Behaviour Change Wheel book³⁰ enabled coding of intervention function(s) and mechanism(s) of action against the COM-B model to describe the behavioural targets of BCTs.

Data synthesis

Patterns between intervention content (including BCTs, intervention function, mechanisms of action, and COM-B behavioural targets) and outcomes were synthesized in a narrative way, in accordance with guidance from Popay et al.³⁷

Quality assessment

The quality and risk of bias of the studies included were assessed using the revised Cochrane Risk-of-Bias Tool for Randomized Trials (RoB 2)³⁸ or the Risk Of Bias In Non-randomized Studies - of Interventions (ROBINS-I) assessment tool,³⁹ depending on study design.

The RoB 2 offers a framework to consider the risk of bias of findings from any form of randomized trial.³⁸ Overall risk of bias ranges from low to high, with 'some concerns' providing an intermediate rating.

The ROBINS-I tool supports consideration of risk of bias from non-randomized studies of the effects of interventions; it compares the effects of two or more interventions.³⁹ Overall, risk-of-bias ratings range from low to critical, with 'lack of information' used where there is no clear indication of risk of bias.

Two reviewers (DY and SC) independently applied the relevant tool and assessed the risk of bias for the studies included in the review. Reviewers compared findings and discussed discrepancies until agreement was reached, with a third reviewer supporting discussions where needed (WH).

RESULTS

Database searches

Database searches identified a total of 8355 studies: MEDLINE (1569); Allied and Complementary Medicine (123); Cumulative Index to Nursing and Allied Health Literature (761); PsycINFO (2403); Embase (1886); Scopus (1085); and the Cochrane Library (528). A total of 1855 duplicates were removed, which left 6470 studies available for screening. Supplementary grey literature searching identified a total of 879 theses: Ethos (20); Open Grey (4); and ProQuest (855).

Selection process

There was substantial agreement between reviewers for the title and abstract screening ($k=0.62$ from 1294 studies; overall agreement of 99%).³⁵ After the initial screening, 86 full texts were taken forward with almost perfect agreement between reviewers ($k=0.82$ from 18 studies; total agreement 94%). The full text of one study could not be located despite multiple attempts.⁴⁰ The main reasons for study exclusion were no reference to parents in the intervention descriptions,

or the focus not being physical or motor function (see Appendix S3 for the full details).

Because interrater reliability of the study title and abstract screening had substantial agreement ($k=0.62$), and full-text screening had almost perfect agreement ($k=0.82$), the identified theses from the grey literature searches were reviewed by one reviewer (DY). A total of 877 theses were removed after title and abstract screening. Two theses were taken forward to full-text review, but neither ultimately met the eligibility criteria.

In total, two studies^{41,42} and one study protocol⁴³ met the inclusion criteria after full-text screening. Four additional studies^{44–47} were identified through manual searching of reference lists (see Figure S1 for details).

Summary of studies

Study and participant characteristics

In total, six studies evaluating six different interventions and one study protocol met the inclusion criteria,^{41–47} with full details provided in Table 1. Studies were published over a 13-year period between 2003 and 2016; all were written in English. Studies were conducted in Australia,⁴⁷ Brazil,⁴¹ Israel,^{42,46} Italy,⁴⁴ and the USA,⁴⁵ none were conducted in the UK.

Studies included a total of 211 participants (ranging from 7 to 87), and all included a mixture of males and females. Participant age varied between studies; however, all participants were aged between 5 and 17 years. Two studies exclusively included participants who sustained a TBI,^{41,44} three included participants diagnosed with an acquired brain injury, with a proportion having sustained a TBI (ranging between 38% and 53% of the sample),^{45–47} and one study had equal proportions of participants diagnosed with TBI and cerebral palsy.⁴² Intervention duration lasted between 2 weeks and 1 year.

Study design

Studies used a range of designs: randomized controlled trial;⁴¹ pilot randomized trial;⁴⁷ feasibility study involving randomization;⁴² feasibility study involving multiple case studies;⁴⁵ non-randomized, self-control study with control and intervention periods;⁴⁶ and before/after comparison study.⁴⁴ Four studies included a control group who either received no care,⁴⁴ received usual care in an outpatient clinic environment,⁴¹ or usual care in the community.^{42,47}

Outcome measures

A range of 19 different outcome measures were used to assess changes in participants' motor function across the six

studies. Only three outcome measures were common to more than one study (10-Metre Walking Test, 2-Minute Walk Test, and energy expenditure index); all three related to walking performance and the studies were conducted by the same lead researcher.^{42,46} Upper-limb dexterity and function were assessed using the highest number of different outcome measures (seven in total), as described in Appendix S4. Due to the heterogeneous outcome measures, meta-analysis was not possible.

Parent involvement in rehabilitation

In this section, we report the different roles that parents have in their child's rehabilitation across studies, from active delivery of rehabilitation exercises to supervising their child.

All studies included an initial training period whereby the recipient of the intervention was trained to deliver and practise the rehabilitation exercises. In one study, parents were the primary focus of training and delivery of rehabilitation exercises to their child with TBI.⁴¹ In this study, parents observed the professionals performing the intervention and assumed increasing responsibility as their competence increased. Parent involvement in their child's rehabilitation was somewhat different in the remaining studies.

Two studies included some parent-delivered rehabilitation whereby a parent received training from therapists to deliver rehabilitation exercises alongside therapists or other hospital staff.^{44,45} Both studies implemented constrained induced movement therapy interventions where a parent codelivered the rehabilitation. Three studies involved a therapist training the child on how to complete the rehabilitation exercises at home,^{42,46,47} with parents also present. In these studies, parents were required to supervise the child, completing the rehabilitation exercises within the home environment.

Training in most studies included a description and demonstration of how to perform the exercises, with an element of tailoring to the participant, for example, individualized goal setting or agreeing dosage based on baseline assessment measures. Some interventions included regular contact from therapists or the research team to review progress, troubleshoot problems, or update goals and plans. In all cases, a parent was present with the child at the time of these follow-up contacts. In addition, some interventions also included diaries and reward charts for monitoring progress.

Context of rehabilitation delivery

Rehabilitation exercises were delivered within the home environment in four of the studies.^{41,42,46,47} In one study, rehabilitation exercises were delivered in a specialist rehabilitation unit,⁴⁵ in the other study, rehabilitation exercises were delivered using a combination of home environment and specialist rehabilitation unit.⁴⁴

TABLE 1 Study and participant characteristics

Study	Location	Study design, duration, and sample size	Population, study setting, recruitment method	Intervention group		Control group		Study/intervention retention and adherence
				Sample size and participant characteristics	Content and description of the intervention	Sample size and participant characteristics	Content of control	
Braga et al. ⁴¹	Brazil	Randomized controlled trial, 1 year, <i>n</i> = 87	Children and young people aged 5–12 years, history of moderate-to-severe TBI sustained 6–30 months before beginning the study Home environment (intervention group) or clinic (control group) Recruited from admission records at a specialist paediatric rehabilitation clinic	<i>n</i> = 44 Age median (SD) = 97.66 (29.61) months 47% female	Parents delivered the rehabilitation intervention Parents underwent an initial 2-week block of training with therapists, goal setting, and biweekly follow-up in the clinic. The intervention included individualized paper-based manuals with illustrations of exercises, which parents delivered to their child at home	<i>n</i> = 43 Age mean (SD) = 96.95 (30.30) months 44% female Other characteristics not reported	Parents received initial education and support. Children received daily outpatient clinic-based rehabilitation	The intervention group retained 38 participants (86%) at follow-up. The control group retained 34 participants (79%) Authors reported that 'the greater loss in the DCD [control] group was due largely to difficulties transporting the child to the clinic daily' Adherence data not reported
Cimolin et al. ⁴⁴	Italy	Before and after the study, 10 weeks, <i>n</i> = 20	Children and young people diagnosed with unilateral paralysis after TBI with documented loss of consciousness for 24 hours or more and a baseline IQ ≥ 60 (intervention group), compared to healthy controls (control group) Inpatient brain injury unit of a rehabilitation hospital and home environment Recruitment completed among inpatients in the brain injury unit	<i>n</i> = 10 Age range 8.8–12.9 years Six had right-sided (dominant) and four had left-sided (nondominant) impairment On average, participants commenced the intervention 0.7 years after injury (range 0.2–1.4 years)	Constraint-induced movement therapy intervention Children wore Posey mitt for 3 consecutive hours per day Three days per week in hospital, therapists led unimanual activities for 1.5 hours and parents led unimanual activities for 1.5 hours Four days per week at home, parents led 3-hour sessions of unimanual activities	<i>n</i> = 10 Age range 7.3–13.6 years	No intervention delivered	No reported loss to follow-up Adherence data not reported

TABLE 1 (Continued)

Study	Location	Study design, duration, and sample size	Population, study setting, recruitment method	Intervention group		Control group		Study/intervention retention and reported adherence
				Sample size and participant characteristics	Content and description of the intervention	Sample size and participant characteristics	Content of control	
Karman et al. ⁴⁵	USA	Feasibility study using multiple case studies, 2 weeks, $n = 7$	Children and young people with acquired brain injury admitted to an inpatient rehabilitation unit. Intervention commenced between 25 days and 2 years after injury Inpatient facility	$n = 7$, TBI = 43% Aged between 7 and 17 years old 28.67% female	Two-week intensive block of constraint-induced movement therapy Posey mitt worn for all waking hours. Six hours of shaping activities daily (on weekdays) with graded difficulty of tasks to accommodate the patient's limitations At least 4 hours of therapy was delivered daily by therapy staff; all other shaping practice was carried out by other staff and parents	No control group	All seven participants completed the intervention and after intervention assessment Adherence data not reported	
Katz-Leurer et al. ⁴⁶	Israel	Feasibility study, non-randomized, self-control study, 4 weeks, $n = 19$	Children and young people with acquired brain injury, aged 5–15 years at the time of the injury. Must be at least 1 year after the onset of the injury Home environment	$n = 19$, TBI = 53% Age mean (SD) = 12.5 (3.1) years 53% female	Child completed rehabilitation under supervision of a parent Introduced to exercise protocol in a clinic environment and required to complete exercises at home under parental supervision (three sets of sit-to-stand, three sets of step-up with each leg daily for at least 3 days per week). Intensity: 60% of individual maximum for the first 2 weeks then up to 80% of individual maximum for final 2 weeks	No control group	High dropout rate of 53% ($n = 10$) Authors reported that Logistics were cited most as the most significant factor [for withdrawal] Exercise recommendations based on baseline results; it was not possible to determine participant adherence	

TABLE 1 (Continued)

Study	Location	Study design, duration, and sample size	Population, study setting, recruitment method	Intervention group		Control group		Study/intervention reported and adherence
				Sample size and participant characteristics	Content and description of the intervention	Sample size and participant characteristics	Content of control	
Katz-Leurer et al. ⁴²	Israel	Feasibility study, randomized study, 6 weeks, <i>n</i> = 20	Children and young people aged 7–13 years, history of cerebral palsy or severe TBI Home environment Recruited as outpatients or former patients of a children's rehabilitation hospital	<i>n</i> = 10, TBI = 50% Age mean (SD) = 8.2 (3.8) years 30% female	Child completed rehabilitation under the supervision of a parent Completed sit-to-stand and step-up exercises on each leg daily, 1 minute rest between sets Exercises 5 days per week, increased from 50% maximum for 2 weeks to 75% maximum thereafter. Intervention period was 6 weeks with follow-up for a further 12 weeks	<i>n</i> = 10, TBI = 50% Age mean (SD) = 9.2 (2.7) years 30% female	Told to continue with regular daily activities, including school and sports	Nine participants in the intervention group completed the intervention. Eight participants were followed up at 12 weeks Participants completed the exercises five times per week as recommended and were deemed to have adhered to the intervention No influences on adherence were reported
Sakzewski et al. ⁴⁷		Pilot randomized trial, 20 weeks, <i>n</i> = 58	Children and young people aged 8–16 years with a history of acquired brain injury Home environment Waitlist randomization using matched pairs	<i>n</i> = 29, TBI = 38% Age mean (SD) = 11 years 10 months (2 years 6 months) 48% female Mainstream education 52%	Child completed the rehabilitation under the supervision of a parent 'Move it to improve it', a Web-based intervention combining cognitive and motor challenges Recommended to complete 30 minutes per day, 6 days per week for 20 weeks	<i>n</i> = 29, TBI = 28% Age mean (SD) = 11 years 11 months (2 years 6 months) 41% female Mainstream education 52%	Received usual care, determined using a questionnaire completed after the intervention period	Participant retention to follow-up was 83.33% for the intervention group and 86.67% for the control group Participants did not adhere to the intervention. Participants completed on average less than 1 hour of rehabilitation per week (17.6 hours over 20 weeks, not 60 hours as recommended)

Decimal years reported as in the original studies. Abbreviations: DCD, direct clinician-delivered [rehabilitation]; TBI, traumatic brain injury.

Adherence to rehabilitation

Adherence is the extent to which an individual's behaviour aligns with a health professional's recommendation.²⁵ No studies specifically reported parental adherence to the delivery of rehabilitation exercises at home. Three studies retrospectively assessed and reported child adherence to recommended rehabilitation exercises with parental supervision. In two studies, adherence data were extracted from self-reported records using paper-based exercise diaries.^{42,46} Another study captured and analysed adherence data electronically⁴⁷ (Table 1).

Summary of interventions

Intervention content and targets

Of the six interventions analysed, two targeted improvements in lower-limb strength and endurance through sit-to-stand and step-up exercises completed at varying intensities.^{42,46} Two targeted improvements in the upper-limb function of children with unilateral paralysis through constrained induced movement therapy.^{44,45} One intervention targeted both motor and cognitive function through an integrated programme of bespoke exercises translated into simple activities using illustrations.⁴¹ One intervention targeted occupational performance, upper-limb function, and visual perception using a multimodal Web-based rehabilitation intervention, that is, 'Move it to improve it'.⁴⁷

When considering the target recipient of the interventions, only one of the six interventions focused solely on parent-delivered rehabilitation to a child after TBI.⁴¹ The remaining studies all explicitly referred to parents being involved in either the delivery of aspects of the rehabilitation^{44,45} or being present when the child received training on the content of the intervention.^{42,46,47} In all instances, parents were requested to supervise their child completing the exercises when parents themselves did not deliver any aspect of the intervention.^{42,46,47}

Behavioural change techniques included in interventions and control groups

In total, 24 BCTs were coded across the six interventions. Interventions included between six⁴⁴ and 16 BCTs^{41,47} with an average of 11.67 BCTs per intervention (Table S1). The intervention target was identified (parent or child) as some interventions involved parent-delivered rehabilitation while others targeted the children themselves. The two most frequently coded BCTs, which featured in all six interventions, were '1.1 Goal setting (behaviour)' and '4.1 Instruction on how to perform the behaviour', each coded 10 times in total across the six interventions. The BCT '1.4 Action planning' was also coded in all six interventions and was coded eight times in total.

Several BCTs were consistently coded together: '1.1 Goal setting (behaviour)' and '1.4 Action planning' were coded together in five of the six intervention descriptions.^{42,44–47} Furthermore, the '4.1 Instruction on how to perform the behaviour', '6.1 Demonstration of the behaviour', and '8.1 Behavioural practice/rehearsal' BCTs were coded together in five of the six interventions.^{41,44–47} These BCTs were coded where participants received instruction or training in preparation for repeating the exercises independently.

In three of the four studies that included a control group, no BCTs could be coded because control groups either received no intervention⁴⁴ or 'usual care'.^{42,47} In one study, three BCTs were coded that were also included in the intervention.⁴¹

Intervention functions identified in intervention and control groups

From the nine possible intervention functions, eight were coded as being present within the interventions; the exception was 'Restriction'. The three most frequently coded intervention functions were 'Enablement', 'Training', and 'Incentivisation' (coded 55, 44, and 17 times respectively, across all interventions).

Within the descriptions of the control groups, three intervention functions were coded: 'Education' (coded once), 'Persuasion' (coded once), and 'Enablement' (coded twice).

Mechanisms of action identified in the intervention and control groups

In total, 19 different mechanisms of action were coded in relation to the identified intervention BCTs. The three most frequently coded were 'Beliefs about capabilities', 'Skills', and 'Goals' (coded 29, 25, and 17 times respectively, across all interventions).

Within the description of the control groups, eight mechanisms of action were coded: 'Knowledge'; 'Beliefs about consequences'; 'Intention'; 'Attitude towards the behaviour'; 'Perceived susceptibility/vulnerability'; 'Social influences'; 'Beliefs about capabilities'; and 'Behavioural regulation' (all coded once).

Components of capability, opportunity, and motivation in the intervention and control groups

From the six individual components of the COM-B model, all were coded as being targeted by the identified intervention BCTs. In descending order: 'Reflective motivation' was coded 85 times; 'Psychological capability' was coded 43 times; 'Physical capability' was coded 34 times; 'Social opportunity' was coded 18 times; 'Automatic motivation' was coded 10 times; and 'Physical opportunity' was coded six times.

Within the control groups, three components of the COM-B model were coded: 'Social opportunity' (coded once); 'Psychological capability' (coded twice); and 'Reflective motivation' (coded twice).

Quality appraisal and risk of bias

Overall, three studies were assessed for risk of bias using the RoB 2 and all were deemed to be at high risk of bias (Appendix S5).^{41,42,47} The main potential sources of bias were the impact of missing outcome data and the measurement of outcomes, with particular concern from lack of assessor blinding.

Two studies were assessed for risk of bias using the ROBINS-I tool.^{44,46} The studies were deemed to be at either serious⁴⁴ or critical⁴⁶ risk of bias (Appendix S6). The main sources of risk of bias were selection of participants to the intervention and deviations from the intended intervention, particularly because of high participant withdrawal rates. Measurement of outcomes with lack of assessor blinding was also problematic.

The feasibility study consisting of multiple case studies⁴⁵ was not assessed for risk of bias because an appropriate tool could not be identified.

DISCUSSION

Parents experience increased stress and significant challenges after their child's TBI.^{3,9} Parents are required to deliver rehabilitation to their child in the home environment after leaving hospital; however, little is known about how parents are supported to do this. For the first time, this systematic review identified and unpacked strategies used to support parents to deliver rehabilitation exercises to their child after TBI.

Six studies evaluating six interventions delivered to 211 participants were analysed. While parents were the target population for this systematic review, only one intervention focused directly on the question of how to support parent-delivered rehabilitation.⁴¹ This may reflect the current lack of awareness and understanding about the parent's role in their child's physical rehabilitation and indicates the lack of emphasis given to this area of clinical research. One intervention, for example, considered parental involvement entailing no more than their mere presence in the room while the child received training from a physiotherapist. Katz-Leurer et al.⁴⁶ described that parents were 'passive observers' in meetings where the child was taught how to complete the rehabilitation exercises; parents were expected to learn the exercises through observation and then supervise their child at home.

The interventions involved parents in their child's rehabilitation in three main ways. First, parents were taught to actively deliver rehabilitation exercises after education from appropriately qualified professionals (e.g.

physiotherapists or occupational therapists).^{41,44,45} Second, parents were supervisors of their child's rehabilitation.^{42,46,47} Finally, parents were involved in the planning and logistic tasks related to their child's rehabilitation; this is particularly evident in that logistical reasons (e.g. travel distance and time) were cited as the main reason for participant withdrawal from studies.^{41,46} It is therefore important for interventions to consider support for parents in all three ways.

We identified common active ingredients across interventions. Three BCTs were present in all interventions: 'Goal setting (behaviour)', 'Action planning', and 'Instruction on how to perform the behaviour'. The 'Goal setting (behaviour)' and 'Action planning' BCTs were frequently coded together, which is appropriate because they are complementary techniques; in circumstances where behavioural goals are defined by context, frequency, duration, or intensity, they require joint coding.³⁶ Additional BCTs that appeared frequently across interventions and were delivered jointly on multiple occasions were those related to instruction, demonstration, and practice. These groups of BCTs are key findings from the review because when active ingredients are grouped, this can aid their delivery and effectiveness.⁴⁸ Goals and planning, as well as training, demonstration, and practice are essential processes required for learning, planning, and implementing rehabilitation exercises. These BCTs all target reflective motivation which, together with capability and opportunity, support the participant to actively engage in the intervention and consciously enact new behaviours through the creation of plans and evaluation that informs the intention to act.^{49,50}

Given the necessary repetitive, long-term nature of rehabilitation exercises required for neuroplasticity, it is somewhat surprising that interventions have not also prioritized the maintenance of delivery of exercises over time. Our analysis revealed that some active ingredients are surprisingly absent from the interventions. The BCT 'Prompts/cues', which considers the environmental or social stimuli for prompting or cueing behaviour, was not coded in any interventions; however, it was present in another systematic review of interventions, with significant positive effect for supporting the maintenance of physical activity.⁵¹ Furthermore, 'Generalization of target behaviour' was also absent; this would include advice to implement rehabilitation exercises outside a specific context (e.g. implementing balance-based exercises in the local park in addition to the home environment). Studies included in this review were primarily feasibility studies conducted over a period of weeks to a few months, which may explain the focus on initiation as opposed to maintenance of rehabilitation exercises.

The nature of repetitive daily physical rehabilitation exercises lends itself well to the development of habits, as noted elsewhere.⁵¹ Habitual behaviours are enacted when a situation triggers an action with little or no conscious forethought, learned through practice and rehearsal.⁵² Habit

also supports the maintenance of behaviours when conscious motivation decreases.⁴⁹ This would go beyond the conscious processes of planning and initiating behaviours to more automatic processes, which are triggered by the environment. The 'Habit formation' BCT was coded only twice across interventions, with coders concluding that the BCT was present in all probability. This is because study authors referred to incorporating rehabilitation exercises into family routines, as opposed to building habits per se.^{41,43} Notably, 'Habit formation' was coded in the two interventions with the longest study durations of the accepted studies: 20 weeks^{43,47} and 1 year.⁴¹ Again, this emphasizes the need for future interventions to include BCTs that support the maintenance of rehabilitation exercise delivery over time.

Similarly, problem-solving is an evidence-based BCT worthy of further consideration in the context of empowering parents to deliver rehabilitation exercises. The 'Problem-solving' BCT was coded six times across interventions; however, these primarily related to professional problem-solving after participant feedback or problem-solving technical issues. According to the BCTTv1, problem-solving is about empowering parents to analyse factors, which helps in overcoming barriers or aiding facilitators in delivering rehabilitation exercises. This could be considered part of the wider discourse around family-centred care and parent-delivered rehabilitation (also referred to as 'parent self-management' in the literature) where support seeks to move from a paternalistic model to one of shared power and ownership.⁵³ Wong Chung et al.⁵³ investigated health care professionals' motivation to support parental self-management when working with children with physical disabilities. They found that around 90% of participants taking part in a mixed-methods study believed that parents should take an active role in their child's rehabilitation, whereas less than 10% considered parents taking the initiative and being independent actors in the rehabilitation process as being important.⁵³ The study additionally found that sharing responsibility could be difficult for professionals as they navigate maintaining authority and control with sharing responsibility with parents. This is echoed in the qualitative synthesis of literature carried out by Lord et al.⁵⁴ relating to parent-delivered therapy interventions for children with cerebral palsy, which highlighted the need for support, trust, and shared decision-making in helping to build trusting relationships.

Four of the six studies included in this review involved mixed samples of children diagnosed with an acquired brain injury or cerebral palsy. Both conditions encapsulate complex neurological disorders that frequently lead to motor impairments; however, they also include a high degree of variability in the nature of the injury and the timing of neurological insult on the developing brain.⁵⁵ The need to support parent-delivered rehabilitation among diverse populations should not be homogenized and assumed. Rather, appropriate investigation and stakeholder engagement must be undertaken to ensure that interventions are created to adequately meet the needs of their end users.²⁴

The findings from this review suggest that much more research is needed to develop theory-based and evidence-based interventions providing support for parents to deliver rehabilitation exercises. There is a need to go beyond the initial education, goal setting, and planning for the delivery of exercises to consider the longer-term, complex nature of rehabilitation delivery in a real-world setting and helping to support the maintenance of delivery of exercises over time.

Strengths, limitations, and directions for future research

This review is the first to examine support for parent-delivered rehabilitation exercises after childhood TBI, generating evidence to inform practice. The fine-grained approach to identifying strategies and coding BCTs is a real strength of this review; however, it is possible that not all BCTs included within the interventions were identified. This is because of insufficient reporting of the intervention content, which limits detailed understanding and the ability to adapt interventions for different contexts.²⁴

Another strength of the review is that risk-of-bias tools for the study methodology were completed by two reviewers. All studies had methodological flaws and were deemed to be at high, serious, or critical risk of bias. This leads to caution about the interpretation of the results. Nonetheless, the primary purpose of the review was to complete an in-depth analysis of the strategies used to support parents to deliver rehabilitation to their child and that has been achieved.

There is a paucity of evidence for parent-delivered rehabilitation exercises for children after TBI and only one randomized controlled trial was identified.⁴¹ This is a limitation of the evidence, which means that there was no possibility for meta-analysis of the outcomes. This is further evidenced by the fact that many of the studies were feasibility studies of new interventions.

The studies identified have some clinical heterogeneity with regard to both the participants included in the studies and the study methodologies used. Using qualitative research, future research should seek to understand the needs of users and other key stakeholders from their own perspectives. This is recommended by best-practice guidance for intervention development and will support the acceptability and usability of interventions.^{24,50} Evidence from the present systematic review and subsequent qualitative research could then be used together to provide an evidence base when coproducing interventions with parents, children, rehabilitation professionals, and other key stakeholders. Such approaches to coproduction will go some way in helping to address power imbalances and better support parent self-management.⁵³

Future research should also seek to provide detailed descriptions about the content of interventions and the underlying theory to provide rigour and transparency to the design process and enable the replication of interventions.²⁴ This will help to develop further evidence about parent-delivered

rehabilitation and suggest which BCTs and elements of interventions are particularly important in supporting behavioural change.

Conclusions

This is the first systematic review to examine in depth how interventions have supported parents to deliver rehabilitation exercises to their child after TBI. The active ingredients and intervention content we identified can be used to inform future theory-based and evidence-based interventions. Our findings suggest that instruction, demonstration, and practice, as well as goal setting and planning, are particularly important elements of interventions aimed at increasing the skills and motivation of parents who deliver or support the delivery of rehabilitation exercises. However, future interventions need to consider the longer-term maintenance of behaviours related to rehabilitation delivery. Intervention developers should consider coproducing interventions and provide clear descriptions of their content to aid evaluation, implementation, and adaptation for different contexts.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

The following additional material may be found online:

Figure S1: PRISMA flow diagram.

Appendix S1: PICO criteria to inform the search strategy.

Appendix S2: Search strategy.

Appendix S3: References excluded after the full-text review.

Appendix S4: Changes in motor function using outcome measurement before and after the intervention.

Appendix S5: RoB 2.

Appendix S6: ROBINS-I.

Table S1: Identified strategies with coded behaviour change techniques, intervention functions, mechanism of action, and targets.

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