The Subacute Rehabilitation of Childhood Stroke

CLINICAL GUIDELINE 2019

Victorian Subacute Childhood Stroke Advisory Committee

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Only names of those who consented for their names to be acknowledged in publications are printed here.

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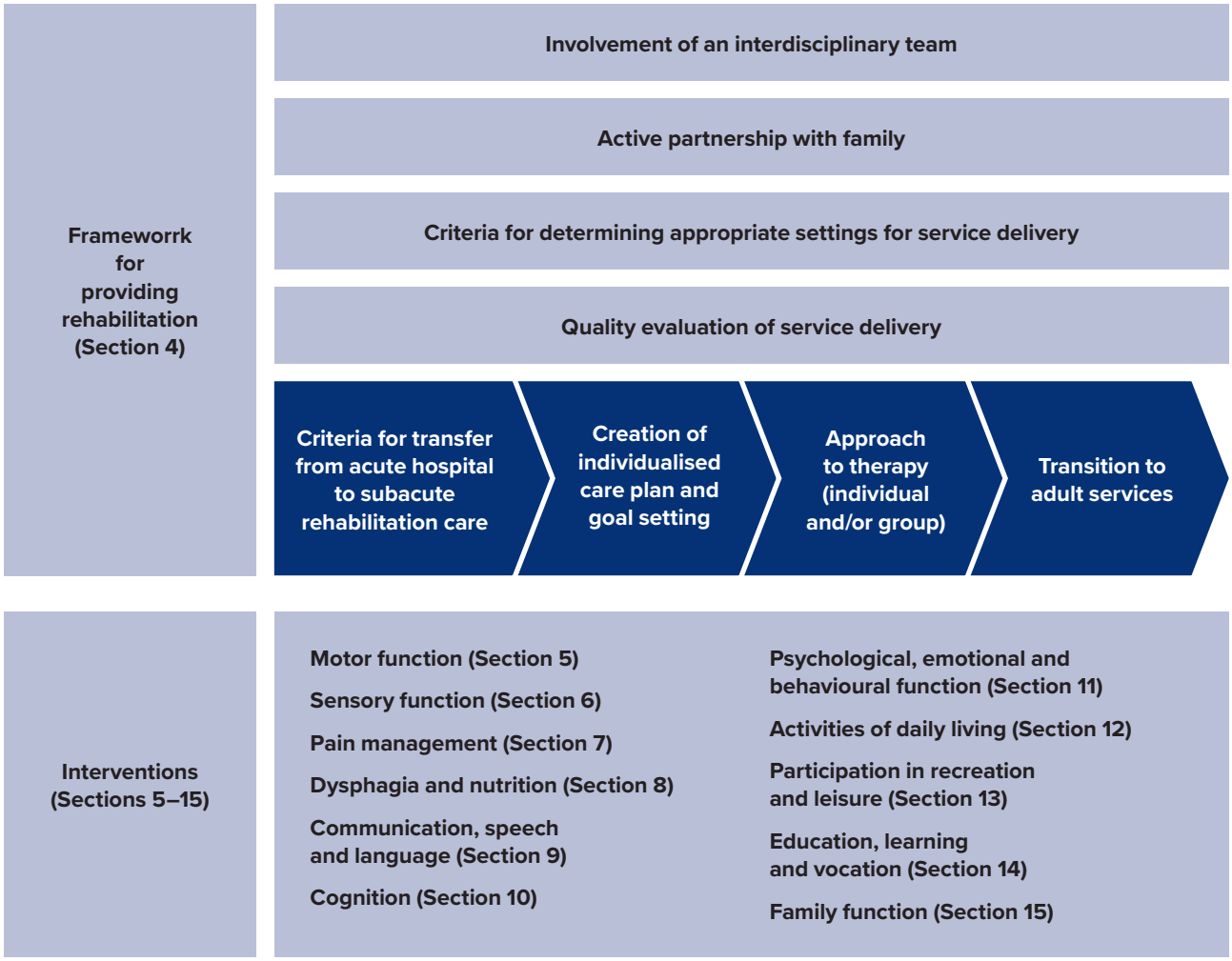
Abbreviations

AIS	Arterial ischaemic stroke
CBR	Consensus-based recommendation
EBR	Evidence-based recommendation
GDC	Guideline Development Committee
mCIMT	Modified constraint induced movement therapy
NHMRC	National Health and Medical Research Council
PSD	Program for Students with Disabilities
PNF	Proprioceptive Neuromuscular Facilitation
rTMS	Repetitive transcranial magnetic stimulation
SCD	Sickle cell disease
VPRS	Victorian Paediatric Rehabilitation Service

1. QUICK REFERENCE GUIDE

Figure 1. Quick reference guide to key recommendations for the subacute rehabilitation of childhood stroke



2. INTRODUCTION

2.1. Background

Stroke is among the top ten causes of death in children and more than half of survivors have long-term disabilities, resulting in a need for high quality, specialist sub-acute medical and rehabilitation services. Contrary to commonly held views, children do not recover better than adults[1]. While relatively rare (estimated incidence: 1.2–7.9 per 100 000[2–4]), the economic cost of childhood stroke is substantial[5]. The lifelong individual, family and societal burden of early stroke is likely to be greater than in adults because children surviving stroke face many more years living with disability. A U.S. case control study estimated an average five year medical cost of $110,921 per child, representing a 15 fold cost increase compared to controls[5]. Of note, this figure does not capture costs of families including loss of income, reduced employment, rehabilitation expenses, and psychosocial consequences for child and family. Costs are higher for childhood than for neonatal stroke, and higher for haemorrhagic than ischaemic stroke[5]. Higher costs correlate with worse impairment, emphasising the importance of rehabilitation to maximise recovery[6].

The key difference between children and adults is that paediatric stroke results in the inability to achieve (rather than lose) functional independence. Therefore the functional, behavioural and social consequences may not be apparent at the time of the stroke event, particularly in very young children, who typically grow into their deficits[1].

2.2. Purpose

The purpose of this guideline is to improve the care of children with stroke by providing health professionals with evidence-based and consensus-based recommendations to assist in rehabilitative treatment following diagnosis of childhood stroke.

2.3. Clinical need for this guideline

There is substantial evidence that coordinated, individualised, interdisciplinary approaches to stroke rehabilitation improve outcomes in adults, but no such systems currently exist for childhood stroke[1,7–9]. Further, there are currently no available clinical guidelines for the subacute care of childhood stroke in Australia. Anecdotal reports from treating clinicians and parent members of the StroKidz childhood stroke advocacy/support group suggest there is currently considerable variation in quality of subacute care. The development of clinical care guidelines and the statewide standardisation of referral and service delivery pathways across the Victorian Paediatric Rehabilitation Service (VPRS) will improve consistency of subacute childhood stroke care.

2.4. Scope and intended users of this guideline

This guideline is aimed at hospital and community-based healthcare professionals involved in the rehabilitative management of children after stroke, including occupational therapists, physiotherapists, education consultants, clinical psychologists, clinical neuropsychologists, speech pathologists, social workers, dietitians, music therapists, doctors, and nurses. This guideline is intended to be used by appropriately qualified health professionals to guide clinical management of rehabilitative care following childhood stroke. Further details on the guideline scope can be found in Appendix 1.

2.5. Target population

This guideline addresses the subacute management and care of acute arterial ischaemic stroke and non-traumatic intracranial haemorrhage in children (aged 29 days to 18 years or until school completion). The scope of this guideline does not include perinatal (aged 28 days or younger at stroke onset), subdural haemorrhage secondary to trauma, spinal stroke syndromes or cerebral venous thrombosis without infarction.

3. METHODOLOGY

3.1. Guideline development committee

A multidisciplinary guideline development committee (GDC) was convened to oversee the development of the guideline. The GDC consisted of a panel of clinical and research experts representing the Victorian Paediatric Rehabilitation Service, tertiary paediatric hospitals and researchers in Victoria. Members of the GDC are listed on page 4 under Steering Committee and Clinical Advisory Group. The GDC developed the purpose, scope and clinical questions of the guideline and carried out critical appraisal and data extraction of publications. All conflicts of interest were declared by the GDC and are recorded in Appendix 2. A copy of the conflict of interest form can be found in Appendix 3.

3.2. Clinical questions

The GDC identified clinical areas to be covered by the guideline and the project coordinator formulated these into structured questions in consultation with the steering committee. The clinical questions were developed based on a framework of Population, Intervention, Comparison and Outcome (PICO). The clinical questions addressed by this guideline are detailed in Table 2.1.

Table 2.1. Clinical questions

Clinical question	
1.	What is the most appropriate framework for providing rehabilitation to children with stroke?
2.	In children with stroke and motor difficulties, which interventions improve outcome?
3.	In children with stroke and sensory deficits, which interventions improve outcome?
4.	In children with stroke and pain, which interventions improve outcome?
5.	In children with stroke and dysphagia or poor nutrition status, which interventions improve outcome?
6.	In children with stroke and speech, language or communication difficulties, which interventions improve outcome?
7.	In children with stroke and cognitive difficulties, which interventions improve outcome?
8.	In children with stroke and psychosocial, emotional or behavioural difficulties, which interventions improve outcome?
9.	In children with stroke and difficulties with activities of daily living, which interventions improve outcome?
10.	In children with stroke and reduced participation in recreation or leisure activities, which interventions improve outcome?
11.	In children with stroke, which interventions improve education, learning and vocation outcomes?
12.	In children with stroke, which interventions improve family function?

3.3. Systematic review

Systematic reviews were conducted to identify studies relevant to the clinical questions to be addressed by the guideline. The search strategies used for the systematic reviews are detailed in Appendix 4. All literature searches were conducted on core databases, including MEDLINE, Embase, Cochrane Library and PsycInfo. Searches were limited to the English language. Studies were included in the review if they i) included children aged between 29 days and 18 years with stroke; ii) examined the rehabilitative treatment of difficulties after childhood stroke; and iii) were published after January 2001. Single case reports and case series with less than five participants were excluded from analyses.

3.4. Appraisal of the evidence

Members from the GDC were assigned to working committees for each clinical question based on their professional expertise. Initial abstract screening of the electronic search results was completed by two members of each working committee independently; differing selections were resolved by a third reviewer. Where reviewers were uncertain about inclusion, the full text article was retrieved.

The included studies were appraised for methodological quality using critical appraisal checklists developed by the Scottish Intercollegiate Guidelines Network (SIGN) and an NHMRC level of evidence[10] was applied to each study (Appendix 5). Evidence summary tables (see Appendix 6) for selected literature informed the summary of relevant literature for each clinical question.

3.5. Delphi survey

In the absence of sufficient evidence, expert opinion via a Delphi survey was used to inform the development of consensus-based recommendations. An online Delphi survey, consisting of three rounds, was used to obtain the expert views of members of the GDC as well as health professionals from around Australia and internationally. Additional Delphi panelists were obtained from the VPRS or identified by GDC members. The Delphi survey involved the participation of 99 healthcare professionals including physiotherapists, occupational therapists, speech pathologists, neuropsychologists, clinical psychologists, social workers, education consultants, music therapists, dietitians, doctors and nurses. Delphi panelists are listed on page 5. The three rounds of the Delphi survey consisted of open-ended and multiple-choice questions. The methods of the Delphi survey are described in Appendix 9.

3.6. Development of evidence-based and consensus-based recommendations

Where sufficient evidence was available, evidence based-recommendations were formed by the relevant working committee, and then reviewed by the steering committee. Evidence-based recommendations were developed using the NHMRC evidence statement form (Appendix 7). The form was used to assess the body of evidence for each clinical question. The body of evidence was evaluated according to the evidence base (e.g., number and quality of studies, level of evidence), consistency of results, clinical impact, generalisability and applicability. Evidence-based recommendations were assigned an NHMRC grade (Appendix 8) based on the quality of evidence and have been referenced [EBR].

Consensus-based recommendations were developed based on the results of the Delphi survey. Questions where at least 75% consensus was reached were used to formulate consensus-based recommendations. These have been referenced [CBR].

3.7. Targeted consultation

The drafted guideline underwent a period of targeted external consultation from June to October 2018. All comments and suggestions were collated and reviewed by the GDC with a consensus process used to modify the guideline.

4. FRAMEWORK FOR PROVIDING REHABILITATION

4.1. Introduction

Children and adolescents with stroke may be treated in a range of settings. Within Victoria, this typically includes initial care on an acute neurology inpatient unit within a tertiary hospital. Referral is generally made to rehabilitation for ongoing care following stabilisation of the medical condition. Rehabilitation may be provided by (i) the acute allied health team, (ii) by a specialised rehabilitation team providing services within the tertiary hospital or in the ambulatory setting, (iii) by a specialised rehabilitation team in the community, or (iv) by non-specialised community therapy providers. Within the adult stroke literature, complete stroke care delivery in the early days and weeks following an acute stroke has been shown to have a significant positive impact on stroke outcomes[11]. However, there is only low level evidence of the benefit of providing a similarly specialised rehabilitation program within the paediatric setting. For adults with stroke, the timeliness and intensity of inpatient rehabilitation interventions as well as the environment in which they are provided have also been found to be significant predictors of patient outcomes post stroke[10].

4.2. Evidence summary

A systematic review was conducted and identified no original research studies reporting on frameworks for providing rehabilitation to children following stroke. Due to the lack of evidence, the following recommendations are based on the clinical experience and expertise of the Delphi panelists.

4.3. Recommendations

Recommendation	Type	Grade
An interdisciplinary team (defined as a group of health professionals from diverse fields who work in a coordinated fashion with the parent and child toward a common goal) is the most appropriate model to achieve optimal outcomes for the child and family after childhood stroke for both inpatient and outpatient rehabilitation	CBR	N/A
The following criteria should be considered in determining when a child should be transferred from acute hospital to subacute rehabilitation care following a stroke: **a)** The child is medically stable or any medical instability is able to be managed by the rehabilitation team **b)** The child has change in function that could benefit from rehabilitation **c)** Rehabilitation goals have been identified	CBR	N/A
The following criteria should be considered in determining when a child should be transferred from subacute rehabilitation to long term community care following a stroke: **a)** Safety of the child in the community and home has been achieved **b)** Current goals are better addressed in the community or are more community-based (e.g., return to school) **c)** Therapy needs have decreased to a level that they can be confidently met in the community setting **d)** The family feels capable and ready to care for the child at home	CBR	N/A

Recommendation	Type	Grade
Subacute rehabilitation is best undertaken in a dedicated centralized tertiary care facility when: **a)** Multiple disciplines are involved and high intensity therapy (over a short period) is required **b)** Some medical assessment and intervention is required but the child is generally medically stable **c)** Therapy cannot be provided in a regional centre as the family is too far from a regional centre, or due to lack of access to: (i) required disciplines, (ii) required intensity of therapy, or (iii) specialised equipment	CBR	N/A
Subacute rehabilitation is best undertaken in a regional hospital facility with generalized knowledge of paediatric stroke rehabilitation when: **a)** Fewer disciplines are involved and/or less intensity is required **b)** The child is medically stable **c)** The family prefers this setting due to social or geographical reasons **d)** The child's fatigue limits their ability to travel	CBR	N/A
Subacute rehabilitation is best undertaken in a regional community facility with generalized knowledge of paediatric stroke rehabilitation when: **a)** Fewer disciplines are involved and less intensity is required. **b)** The child is medically stable. **c)** The family prefers this setting due to social or geographical reasons. **d)** The child is less fatigued and able to travel to appointments. **e)** The child's goals are best met in the school or community setting. **f)** The child is at a safe functional level for the family to manage care at home.	CBR	N/A
Group therapy should be considered in addition to standard individualised therapy in the rehabilitation of children following childhood stroke	CBR	N/A
Individualised therapy only is most appropriate when: **a)** Goals are specific to the child **b)** There are issues with distractibility, cognitive dysfunction, and psychological issues and/or over-stimulation **c)** There is a need to frequently modify therapy to address gains **d)** Privacy is required	CBR	N/A

Recommendation	Type	Grade
Group therapy, in addition to individualized therapy, is most appropriate when: **a)** Goals are broad or generic **b)** There are sufficient numbers of children working towards similar goals at the same time **c)** Goals focus on social and communication skills **d)** Goals focus on common physical skills e.g. riding a bike, running skills	CBR	N/A
The child's family should be involved at all stages of rehabilitative care	CBR	N/A
In particular, the child's family should be involved in the following aspects of rehabilitation: **a)** Creation of the individual care plan **b)** Setting goals **c)** Active involvement in therapy sessions	CBR	N/A
Clear communication with the family should be facilitated by family meetings and by ensuring all communication includes the child's family	CBR	N/A
The Canadian Occupation Performance Measure (COPM) should be used when setting rehabilitation goals with a child with stroke and their family	CBR	N/A
The following processes should be included in the transition from paediatric to adult services following childhood stroke: **a)** Early discussion regarding transition **b)** Education to empower the child for autonomy, ability to access services, advocate for their own needs, and negotiate the system **c)** A key contact person to assist with transition **d)** Identify and liaise with the relevant adult service to which transition will occur **e)** Establish clearly defined referral pathway between paediatric and adult services **f)** Ensure joint appointments between consultants in the paediatric and adult services	CBR	N/A
A transition coordinator at rehabilitation sites should be involved in assisting in the transition between paediatric and adult services following childhood stroke	CBR	N/A
The quality of rehabilitation services for children with stroke should be actively monitored. This should include service level outcome measures as well as consumer satisfaction surveys. Outcome measures should be benchmarked against similar services and quality improvement projects should be encouraged.	CBR	N/A

CBR = Consensus-based recommendation

5. MOTOR FUNCTION

5.1. Introduction

Long-term neurodevelopmental disability occurs in 50% of childhood strokes[12]. There is a need for high-quality, evidence-based medical and rehabilitation services for these children and their families. Childhood stroke results in difficulty achieving functional independence. Age at onset of acute ischemic stroke influences motor outcomes and rates of recovery[12]. Hemiplegia is the most common acute clinical sign of childhood AIS and is present in 72% to 90% of cases. Estimates of the prevalence of chronic hemiplegia vary from 25% to 56%[12]. Appropriate, timely interventions targeting motor impairment are crucial at all stages following childhood stroke to optimise function and participation in everyday activities.

5.2. Evidence summary

A systematic review was conducted and identified three studies[13–15], which reported on interventions to improve motor function in children with stroke. Two papers were controlled trials[14,15] and one was a case series[13]. The level of evidence was classified as level II for one study[15], level III for the second study[14] and level IV for the third study[13]. Further details on each study are provided within the evidence tables (Appendix 6).

Kirton and colleagues[15] provide preliminary evidence for repetitive transcranial magnetic stimulation (rTMS) as a feasible intervention to improve grip strength of impaired upper limb after childhood stroke. However, this study is limited by a small sample size (n=10).

Gordon and colleagues[13] investigated the feasibility, tolerability and effect of modified Constraint-Induced Movement Therapy (mCIMT) in children with hemiparesis after AIS. This study was a small case series of six children, but findings show some promise for the use of mCIMT for improvement in goal attainment. No significant improvements in sensorimotor function nor quality of upper limb movement were found. Children and parents were positive about mCIMT, indicating feasibility and tolerability of the intervention.

Khalid and colleagues[14] provide some data support for the use of Proprioceptive Neuromuscular Facilitation (PNF) in the improvement of muscle strength. This study has a larger sample size (n=50) than the other two studies, however it was poorly described, limiting the generalisability of findings.

There is no consistency amongst the three studies as they are all investigating different aspects of motor interventions. Due to the limited and poor quality of available evidence, no EBR could be developed. The following recommendations are based on the clinical experience and expertise of the Delphi panelists.

5.3. Recommendations

Recommendation	Type	Grade
Goal-directed therapy[a] incorporating motor learning principles[b] (including task-specific[c], repetitive and intensive practice[d]) should be considered to improve motor difficulties after childhood stroke	CBR	N/A
Bimanual therapy approaches should be considered to improve motor difficulties after childhood stroke	CBR	N/A

CBR = Consensus-based recommendation

[a] Goal-directed therapy: Therapy based on child-/parent-/therapist-identified meaningful goals[16]

[b] Motor learning principle: Includes intensive practice which is meaningful for the child; active participation of the child; increased practice to increase learning; variable, not constant, task practice; non-repetitive practice order[17]

[c] Task-specific: Intervention based on the skills needed for a task, so training task and goal are similar[18]

[d] Intensive practice: Greater than two sessions per week[19]

6. SENSORY FUNCTION

6.1. Introduction

Childhood stroke can result in a range of sensory impairments, including lost or altered sensation of a limb, visual defects, and visual or sensory neglect, in approximately 21% of children[20]. Such difficulties may influence movement performance, sensorimotor rehabilitation, and body awareness, and may also have implications for safety in functional daily activities.

6.2. Evidence summary

A systematic review was conducted and identified no studies reporting on interventions for the treatment of sensory deficits in children following stroke. Due to the lack of evidence, the following recommendations are based on the clinical experience and expertise of the Delphi panelists.

6.3. Recommendations

Recommendation	Type	Grade
Repeated practice or task-based practice should be considered to improve sensory difficulties after childhood stroke	CBR	N/A
Graded sensory exposure should be considered to improve sensory difficulties after childhood stroke	CBR	N/A
Use of vision to provide sensory feedback about limb position should be considered to improve sensory difficulties after childhood stroke	CBR	N/A
Environmental modifications should be considered to assist children with sensory difficulties after childhood stroke	CBR	N/A

CBR = Consensus-based recommendation

7. PAIN MANAGEMENT

7.1. Introduction

Pain following stroke has been described in the adult population, and can have various aetiologies, including neuropathic and musculoskeletal causes. Post-stroke headache-related pain has been described in the childhood population, although its mechanism and management is unclear. Similarly, little is described in the literature about what interventions improve outcomes in pain prevention and quality of life in the paediatric population following stroke.

7.2. Evidence summary

A systematic review was conducted and identified no studies reporting on interventions for the treatment and prevention of pain in children following stroke. Due to the lack of evidence, the following recommendations are based on the clinical experience and expertise of the Delphi panelists.

7.3. Recommendations

Recommendation	Type	Grade
Multidisciplinary pain management approaches for ongoing pain and a multifaceted approach should be considered to manage pain after childhood stroke	CBR	N/A
Medications should be considered to manage pain after childhood stroke	CBR	N/A
Prevention strategies[a] should be considered to manage pain after childhood stroke	CBR	N/A
Psychological approaches[b] should be considered to manage pain after childhood stroke	CBR	N/A

CBR = Consensus-based recommendation

[a] Prevention strategies may include: correct alignment, protect at-risk joints, maintain joint range of motion, monitor bony growth over time, hip surveillance, spinal surveillance

[b] Psychological approaches may include Cognitive Behavioural Therapy, mindfulness, Acceptance and Commitment Therapy, meditation

8. DYSPHAGIA AND NUTRITION

8.1. Introduction

Childhood stroke can impair swallowing function and place children at risk for aspiration and resultant pneumonia. The ability to maintain adequate and safe oral nutrition and hydration requires the integration of behaviour, cognition and a functional oropharyngeal swallowing mechanism in a highly coordinated, complex act[21]. Surveillance is important for secondary medical complications from stroke such as aspiration[22]. Aspiration can lead to severe and possibly irreversible pulmonary morbidity[23].

Dysphagia is a complex disorder and can range in severity from mild to severe. There are different types of dysphagia depending on the location of the stroke and the specific nerves and musculature affected by childhood stroke. Cognitive impairments, positioning and carer feeding skills also impact on functional swallow ability. Dysphagia can be arbitrarily assigned to the location of the impairment: oral-preparatory phase, oral phase, pharyngeal phase and oesophageal phase of the swallow. Children may have impairments in one or all of these phases.

Dysphagia may cause other complications such as failure to maintain an adequate nutritional intake and hydration[23]. If adequate nutrition and hydration are unable to be maintained from oral intake, alternative feeding methods such as nasogastric tubes or gastrostomy (PEG) are commonly considered.

8.2. Evidence summary

A systematic review was conducted and identified no studies reporting on interventions for the treatment of dysphagia and poor nutritional intake in children following stroke. Due to the lack of evidence, the following recommendations are based on the clinical experience and expertise of the Delphi panelists.

8.3. Recommendations

Recommendation	Type	Grade
Dietary modifications and adjustment of food consistency should be considered to manage dysphagia and poor nutritional intake after childhood stroke	CBR	N/A
Adjustments to environment and equipment should be considered to manage dysphagia and poor nutritional intake after childhood stroke	CBR	N/A
Nasogastric tube feeding, percutaneous endoscopic gastrostomy, enteral feeding or gastrostomy should be considered after stroke to manage severe dysphagia only	CBR	N/A
Strategies or techniques[a] should be considered to manage dysphagia and poor nutritional intake after childhood stroke	CBR	N/A

CBR = Consensus-based recommendation

[a] Strategies or techniques may include chin tuck, jaw support, head rotation, double swallow, cyclic ingestion, effortful swallow, take a smaller mouthful, exercises such as shaker, thermal stimulation, pacing, visual feedback for swallowing, or systematic desensitisation

9. COMMUNICATION, SPEECH AND LANGUAGE FUNCTION

9.1. Introduction

Childhood stroke may result in a range of speech, language and communication impairments. Specific difficulties include speech production deficits such as dysarthria,[24,25] as well as a broad range of language profiles affecting both receptive and expressive language abilities[26,27] including naming deficits, reading difficulties[28] and social language skills[29,30]. Unlike adult stroke, it appears that impairments in these domains may occur regardless of the hemisphere affected[31].

Few studies have investigated the effectiveness of treatment for communication, speech and language difficulties following childhood stroke. A small number of single-case reports have reported benefits of speech and language therapy for children suffering speech, language, literacy and communication difficulties following stroke [32–34].

9.2. Evidence summary

A systematic review was conducted and identified no studies reporting on interventions for the treatment of communication, speech and language difficulties in children after stroke. Case studies of fewer than five children were excluded, as such the studies referred to in the previous section were not included. Due to the lack of evidence, the following recommendations are based on the clinical experience and expertise of the Delphi panelists.

9.3. Recommendations

Recommendation	Type	Grade
Functional communication practice[a] should be considered to improve communication difficulties after childhood stroke	CBR	N/A
Therapy to improve language difficulties[b] should be considered after childhood stroke	CBR	N/A
Articulation or phonological therapy[c] should be considered to improve speech intelligibility after childhood stroke	CBR	N/A
Augmentative and alternative communication[d] should be considered after childhood stroke	CBR	N/A

CBR = Consensus-based recommendation

[a] Functional communication practice may include education or training of a communication partner, prompting hierarchy, task-based practice or social skills training

[b] Therapy to improve language difficulties may include constraint-induced therapy, word finding therapy, working on comprehension in functional settings, visual and key word cues, modified melodic intonation therapy and musical speech stimulation, syntactic or semantic therapy, language drills, or literacy intervention

[c] Articulation or phonological therapy may include speech sound disorder therapy, rhythmic activities, pacing, articulation drills or rhythmic speech cuing

[d] Augmentative and alternative communication may include Dynavox, picture board, gestures or electronic tablets

10. COGNITION

10.1. Introduction

Childhood stroke is known to be associated with significant cognitive sequelae which may impact on development, learning and quality of life. Research in childhood stroke populations suggests that a broad range of cognitive domains can be affected by stroke. Variable findings have been reported in relation to general intellectual function. While children may perform within the lower end of the normal range, they perform significantly lower than their healthy peers[35–37]. Specific deficits identified include the domains of speed of information processing[36], attention and working memory[36,38], memory and learning[39], visuo-spatial function[36], language[39] and executive functions[38,40].

Cognitive outcomes after childhood stroke are known to vary and are influenced by a range of factors including underlying etiology, site and extent of lesion[35,37,41], associated complications, developmental stage at time of stroke[39] and environmental factors.

Cognitive deficits have potential to impact broadly on the child's daily functioning following stroke and have important implications for future learning, vocational outcomes and quality of life. Understanding the child's individual cognitive profile and implications for daily function is an important aspect of designing appropriate rehabilitation interventions and maximizing outcomes.

10.2. Evidence summary

A systematic review was conducted and identified three studies[42–44] which reported on interventions to improve cognitive function in children after stroke. Of the three studies, two were case-control studies[42,43] and one was a case series[44]. The level of evidence was classified as level III for two of the studies[42,43] and level IV for the third study[44]. Sample sizes were very small, ranging from six to nine children. Further details on each study are provided within the evidence tables (Appendix 6).

Two studies consisted of children with sickle-cell disease (SCD) related infarcts[42,43]. All the studies employed working memory or memory training strategies and all reported beneficial results from the intervention to aspects of working memory and memory. None of the studies investigated outcomes of general intellectual abilities, attention or information processing, executive or visuo-spatial functions.

Two of the studies addressed the relative benefit of cognitive strategy training when paired with tutoring, relative to tutoring alone, and found beneficial effects[42,43]. Results suggest that specific cognitive domains may benefit from cognitive strategy training (compensatory techniques), and to a lesser extent, cognitive retraining. These domains were working memory, short term memory and recall. However, the particular populations and population characteristics (age, time since stroke etc.) that would benefit most from these interventions is unclear given the small sample size and the limited number of studies conducted.

Interventions varied in method (face-to-face, computer), location of delivery (home, school-based), and personnel involved in service delivery (rehabilitation professionals, community service providers, education personnel, families) across the three studies. There was also significant variability in the duration (2 years; 5–7 weeks) and intensity (daily vs weekly) of interventions. Dosage of treatment required to gain benefit relative to time and resource cost of intervention was not examined.

The age cohort was limited to middle childhood so generalisability to younger or older children is unknown. Children with SCD were represented in two of the three studies and it is unclear if those findings can be generalised to a broader childhood stroke population or different aetiologies. As the studies focus on limited cognitive domains, it is also difficult to generalise to strategy training or cognitive retraining in a broader sense.

Due to the low quality of evidence and the limited cognitive domains covered, recommendations based on the clinical experience and expertise of the Delphi panelists were also developed.

10.3. **Recommendations**

Recommendation	Type	Grade
Strategy training interventions improve aspects of memory (short term memory and delayed cued recall) after childhood stroke	EBR	D
Compensation techniques[a] should be considered to assist children with cognitive difficulties after childhood stroke	CBR	N/A
Environmental adaptation[b] should be considered to assist children with cognitive difficulties after childhood stroke	CBR	N/A
Psychoeducation for the family and school, and the implementation of cognitive and behavioural strategies for school and home environments should be considered to assist children with cognitive difficulties after childhood stroke	CBR	N/A
Awareness of fatigue and strategies to reduce fatigue should be considered to assist children with cognitive difficulties after childhood stroke	CBR	N/A

CBR = Consensus-based recommendation; EBR=Evidence-based recommendation

[a] Compensation techniques may include simplifying instructions, 1:1 instructions, written instructions instead of verbal, use of visual cues and schedules, allowance of additional time, breaking down tasks into components, breaking information into smaller chunks, reducing the number of stages in a command, or electronic memory aids such as phone reminders, calendars, and electronic organisers

[b] Environmental adaptations may include reducing stimuli, lighting, avoiding overstimulation, decreasing distraction in the classroom, rest periods and/or augmentative communication devices

11. PSYCHOSOCIAL, EMOTIONAL AND BEHAVIORAL FUNCTION

11.1. Introduction

Following stroke, children may exhibit a range of internalising (anxiety, inattention, psychosomatic complaints) and externalising (aggression, hyperactivity, emotional lability, impulsivity) behavioural problems[45]. Psychosocial, emotional and behavioral difficulties are often some of the most distressing and enduring symptoms reported by families following a childhood brain injury[46,47]. Problems in these areas are also associated with long-term adjustment issues, including mental health problems, poorer quality of life, as well as lower academic performance and vocational attainment.

11.2. Evidence summary

A systematic review was conducted and identified no studies reporting on interventions for the treatment of psychosocial, emotional and behavioural difficulties in children following stroke. Due to the lack of evidence, the following recommendations are based on the clinical experience and expertise of the Delphi panelists.

11.3. Recommendations

Recommendation	Type	Grade
Therapy, counselling and support for the family should be considered to improve psychosocial, emotional and behavioural difficulties in children after childhood stroke	CBR	N/A
Psychoeducation on the impact of stroke on emotional and behavioural function to parents and teachers should be considered after childhood stroke	CBR	N/A
Behavioural management interventions[a] should be considered to improve psychosocial, emotional and behavioural difficulties in children after childhood stroke	CBR	N/A

CBR = Consensus-based recommendation

[a] Parent training interventions may include the Triple P parenting course or the Signposts Program for Building Better Behaviour

12. ACTIVITIES OF DAILY LIVING

12.1. Introduction

Activities of daily living is an encompassing term that refers to an individual's performance of tasks across the occupational domains of self-care, productivity/education and leisure. Whilst impairment of anatomical and physiological functions are routinely detailed within stroke literature, the impact of these impairments on children's capacity to achieve independence in the activities they have to do, want to do, or need to do is not well quantified and rarely explored[48,49].

Children who have hemiplegia after stroke may find common bimanual self-care tasks such as learning to tie shoelaces, coordinating use of a knife and fork, managing buttons and zips, opening containers and tying hair up challenging to master. School-based goals may vary from managing school bags, storage tubs and books, to taking lids off marker, and opening lunchboxes and yoghurt containers. In the playground, negotiating climbing frames or playing on monkey bars often present challenges to be addressed. Children may identify leisure goals such as learning to ride a bike, choosing a sport to play or identifying an appropriate instrument to learn. The age at onset of the condition determines whether a child is relearning skills or acquiring new ones and this can influence choices made regarding returning to known activities or mastering new ones.

12.2. Evidence summary

A systematic review was conducted and identified no studies reporting on interventions for the treatment of difficulties with activities of daily living in children following stroke. Due to the lack of evidence, the following recommendations are based on the clinical experience and expertise of the Delphi panelists.

12.3. Recommendations

Recommendation	Type	Grade
Goal-directed therapy[a] incorporating motor learning principles[b] (including task-specific[c], repetitive and intensive practice[d]) should be considered in improving difficulties with activities of daily living in children after childhood stroke	CBR	N/A
Support equipment and environmental adaptations[e] should be considered in improving difficulties with activities of daily living in children after childhood stroke	CBR	N/A

CBR = Consensus-based recommendation

[a] Goal-directed therapy: Therapy based on child-/parent-/therapist-identified meaningful goals[16]

[b] Motor learning principle: Includes intensive practice which is meaningful for the child; active participation of the child; increased practice to increase learning; variable, not constant, task practice; non-repetitive practice order[17]

[c] Task-specific: Intervention based on the skills needed for a task so training task and goal are similar[18]

[d] Intensive practice: Greater than two sessions per week[50]

[e] Environmental adaptations may include utensils, rails, home modifications, Velcro, nonslip mats, pickup stick, sock donner and/or long handled shoe horn

13. PARTICIPATION IN RECREATION AND LEISURE

13.1. Introduction

Children with motor impairments including difficulties with motor control, muscle tone or balance, experience significant difficulties in participating in physical play and leisure[51]. These difficulties are likely to be worsened in children with stroke due to additional cognitive impairment. Research in adult stroke has shown that behavioural interventions can be used to increase what an individual has the capability to do as well as what they actually do in real life[52]. However, little is known about factors and interventions to improve participation in recreation and leisure for children with stroke.

The World Health Organisation developed the International Classification of Functioning, Disability and Health (ICF) framework incorporating biological, individual and social perspectives as components of illness and health. The core components of the ICF are impairment (of body structure or function), activity and activity limitations, and participation and participation restrictions. In children with stroke, factors explaining variation in participation in recreation and leisure are likely to include: impairment (e.g. weakness, pain, cognition); activity limitations (difficulty walking, poor coordination, difficulty with communication); personal factors such as the child's preferences, emotional stability and motivation; and environmental factors such as the parents' preferences and behaviour, the child's school's perceptions of the child's problems, where the child lives and their local supports.

13.2. Evidence summary

A systematic review was conducted and identified no studies reporting on interventions for the treatment of reduced participation in recreation and leisure actives in children following stroke. Due to the lack of evidence, the following recommendations are based on the clinical experience and expertise of the Delphi panelists.

13.3. Recommendations

Recommendation	Type	Grade
Goal-directed therapy[a] incorporating motor learning principles[b] (including task-specific[c], repetitive and intensive practice[d]) should be considered in improving participation in recreation and leisure activities in children after childhood stroke	CBR	N/A
Providing education to parents, the child's school and community regarding effective individualised strategies to encourage integration and participation should be considered in improving participation in recreation and leisure activities in children after childhood stroke	CBR	N/A
Providing support to the family to find clubs/groups that are open to, and supportive of, children with additional needs, to ensure supported transition into appropriate activity, should be considered in improving participation in recreation and leisure activities in children after childhood stroke	CBR	N/A
Task-specific training should be considered in improving participation in recreation and leisure activities in children after childhood stroke	CBR	N/A

CBR = Consensus-based recommendation

[a] Goal-directed therapy: Therapy based on child-/parent-/therapist-identified meaningful goals[16]

[b] Motor learning principle: Includes intensive practice which is meaningful for the child; active participation of the child; increased practice to increase learning; variable, not constant, task practice; non-repetitive practice order[17]

[c] Task-specific: Intervention based on the skills needed for a task so training task and goal are similar[18]

[d] Intensive practice: Greater than two sessions per week[50]

14. EDUCATION, LEARNING AND VOCATION

14.1. Introduction

Childhood stroke can result in a range of acute and longer-term cognitive, physical and behavioural difficulties that may adversely impact the accessibility of educational and vocational opportunities for the child. However, these outcomes vary widely. When compared to same-aged peers, children who suffer stroke experience various cognitive difficulties, although intellectual outcome has been broadly documented within the lower end of normative ranges[36]. It is in more specific cognitive domains that children who suffer stroke demonstrate greatest difficulties when compared to their peers, including information processing and attention, visuoconstructive skills, and short-term memory[36]. Other factors such as fatigue, emotional and behavioral difficulties, and physical deficits are less well documented and may impact on a child's ability to meaningfully access educational and vocational opportunities. Further, hospitalisation, attendance at medical and rehabilitation appointments, and medically required restrictions are likely to disrupt a child's attendance in educational and vocational activities. Within current funding mechanisms, children often fail to meet eligibility criteria for the Program for Students with Disabilities (PSD). The individual course of recovery for each child is uniquely shaped by a variety of factors. These factors must be considered when undertaking assessment and designing interventions to maximize educational and vocational outcomes. The ultimate goal of supporting children with stroke is to maximise educational pathways and to optimize vocational options into adulthood.

14.2. Evidence summary

A systematic review was conducted and identified two studies[42,43] which reported on interventions to improve education, learning and vocation in children after stroke. These two studies were also identified in the cognition question. Both were case-control studies[42,43] and the level of evidence was classified as level III for each of them. Further details on each study are provided within the evidence tables (Appendix 6).

Neither study measured participation or engagement in school, instead focusing on specific cognitive skills (memory) required for learning. They both employed memory training strategies and reported beneficial results from the intervention to aspects of memory. Results suggest that specific cognitive domains may benefit from cognitive strategy training (compensatory techniques), and to a lesser extent, cognitive retraining.

The age cohort was limited to childhood so generalisability to younger or older children is unknown. These studies consisted of children with SCD only, therefore it is unclear if these findings can be generalised to a broader stroke population of varying aetiology.

There is limited direct evidence of the impact of intervention on school and/or vocational outcomes for participants. These studies explored memory, which is only one aspect of academic achievement. Due to the low quality of evidence and the very specific domain covered, recommendations based on the clinical experience and expertise of the Delphi panelists were also developed.

14.3. **Recommendations**

Recommendation	Type	Grade
Strategy training interventions improve aspects of memory (short term memory and delayed cued recall) after childhood stroke	EBR	D
Supported, graded return to school or a return to school program should be considered in improving education, learning and vocational attainment after childhood stroke	CBR	N/A
Psychoeducation to school teachers along with assistance and support for the adaptation of programs (i.e. adapting specific sports for individual participation) should be undertaken in improving education, learning and vocational attainment after childhood stroke	CBR	N/A
Adjustments to school curriculum, modification of expectations and an Individual Learning Plan (ILP)[a] should be considered in improving education, learning and vocational attainment after childhood stroke	CBR	N/A
Modifications to school environment via assistive devices[b] and supportive equipment[c] should be considered in improving education, learning and vocational attainment after childhood stroke	CBR	N/A

CBR = Consensus-based recommendation; Evidence-based recommendation

[a] Adjustments to the school curriculum may include tutoring, extra funding, extra time +/- scribe in exams, and/or varied educational programs

[b] Assistive devices may include wheelchairs for outgoings or sport

[c] Supportive equipment may include: laptop, electronic device or tablet, communication device and/or apps or computer programs

15. FAMILY FUNCTION

15.1. Introduction

Childhood stroke is an unexpected event that can have a significant impact on a child's family. Family members may experience trauma and grief responses, cumulative stressors, challenges to their way of coping, increased strain on resources, burden of care and social disadvantage related to their child's stroke[53–59]. Family functioning may be an important predictor of childhood stroke outcomes[58,60,61]. Families can experience changes to function in relation to roles, routines, division of tasks and communication patterns as they adapt to the changed needs of the injured child[61–63]. Family interventions following childhood stroke need to support the maintenance of family functioning while the family unit makes the necessary changes to care for the injured child[64–67].

15.2. Evidence summary

A systematic review was conducted and identified no studies reporting on interventions for family function in children following stroke. Due to the lack of evidence, the following recommendations are based on the clinical experience and expertise of the Delphi panelists.

15.3. Recommendations

Recommendation	Type	Grade
Family involvement in planning and clear communication with the family should be considered in improving family function after childhood stroke	CBR	N/A
Education and provision of information about stroke should be considered in improving family function after childhood stroke	CBR	N/A
Early involvement of social work support for practical aspects[a] should be considered in improving family function after childhood stroke	CBR	N/A
Family therapy should be considered in improving family function after childhood stroke	CBR	N/A

CBR = Consensus-based recommendation

[a] Financial support, parking vouchers, health care card

16. FUTURE RESEARCH PRIORITIES

While there has been an increase in research characterising outcomes following childhood stroke, few studies have investigated the efficacy of interventions and therefore, the quality of evidence generated from available studies remains low. In contrast, there is a greater amount of high quality evidence to guide rehabilitation interventions in adults[68], emphasising the need for higher quality research to close the gap in knowledge for the paediatric population. Given the low incidence of childhood stroke, multi-centre collaborations are the key to providing meaningful research evidence for the efficacy of rehabilitation interventions.

The literature review, conducted as part of the development of these guidelines, identified many areas of rehabilitation for childhood stroke that would benefit from well-designed research. While there was a small amount of research evidence available to guide clinical decision-making around treatment strategies for cognition and education, there was no specific research evidence available to guide treatment strategies and interventions targeting other functional domains. Therefore, identifying priority areas for research in partnership with key stakeholders, including health professionals, as well as young people with stroke and their families, will help to set a research agenda for childhood stroke that is informed by the expressed needs of key stakeholders[69,70].

The non-consensus in some areas identified by the Delphi process represent important target areas for research into understanding the preferences of health professionals, children and families. More specifically, research is required to understand the preferences of health professionals, children and families, regarding the most appropriate timing of initial involvement of the rehabilitation team following admission to the acute service; and to understand the barriers and facilitators to families accessing their child's health information through the electronic medical record.

Work is also required to explore the effectiveness of guideline implementation in a broader Australian health care setting and to measure their impact on improving health outcomes for children affected by stroke. The National Stroke Foundation have conducted a series of nationwide audits of rehabilitation for adults with stroke[71]. These audits allow for the tracking of service delivery against the adult Clinical Guidelines for Stroke Management 2017[68]. The data, which are used to review service delivery in order to improve the quality of stroke rehabilitation throughout Australia, have seen improvements over time in the quality of care. Adopting a similar approach for childhood stroke would allow for the identification of areas where rehabilitation services are working well, as well as areas requiring improvement.

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