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EXPERT-CONSENSUS REPORT

Pediatric Intracerebral Hemorrhage Management—Consensus Statement of the International Pediatric Stroke Organization—Part 2: Outcomes, Rehabilitation, and Transition to Adulthood

Christine Mrakotsky, PhD; Janette A. Mailo, MD; Mathilde Chevignard, MD, PhD; Nomazulu Dlamini, MBBS, MSc, PhD; Christine K. Fox, MD, MAS; Heather J. Fullerton, MD, MAS; Laura L. Lehman, MD, MPH; Grégoire Boulouis, MD, PhD; Michaela Waak, MD

ABSTRACT: Pediatric hemorrhagic stroke can lead to significant neurologic, cognitive, and behavioral morbidities that often emerge over time and can impede long-term academic, vocational, and socioemotional function. While many of the existing data stem from studies in arterial ischemic stroke, functional outcomes in hemorrhagic stroke, and particularly pediatric intracerebral hemorrhage, remain largely understudied. Extrapolating findings from ischemic stroke can be challenging, as there are notable differences in care and potentially in outcomes for hemorrhagic stroke. The primary goal of this consensus statement by a multidisciplinary group of stroke experts is to provide a review of the current literature on neurologic, cognitive, behavioral, and socioemotional outcomes after hemorrhagic stroke. Neurologically, children with pediatric intracerebral hemorrhage often experience motor deficits, including hemiparesis and coordination issues, as well as cognitive impairments affecting attention, memory, and executive function. Behavioral and emotional problems, such as depression, and social difficulties can also occur. Data on academic attainment are also presented, along with considerations regarding long-term outcomes and the transition to adulthood. We further examine a variety of key determinants predicting outcomes, including medical, demographic, familial, and socioeconomic factors, as well as current research on rehabilitation, with an emphasis on gold-standard guidelines for clinical interventions. Given the complexity of outcome measurement in pediatric hemorrhagic stroke and the lack of uniform tools for assessing outcomes across diverse populations, we propose guiding principles for outcome measurement, along with examples of domain-specific tools. Finally, we discuss the limitations of the current literature and outline goals for future clinical practice and research.

Key Words: behavioral and socioemotional morbidities ■ neurologic and cognitive outcomes ■ outcome measurement ■ pediatric hemorrhagic stroke ■ rehabilitation

See Editorial by Jordan and Kirton.

Over the past two decades, our understanding of person-centered outcomes following arterial ischemic stroke (AIS) in children and newborns has dramatically improved. However, our knowledge of the neurologic, cognitive, behavioral, and functional outcomes following pediatric hemorrhagic stroke

Correspondence to: Laura L. Lehman, MD, MPH, Department of Neurology, Boston Children's Hospital, 300 Longwood Avenue Fegan 11, Boston, MA 02115. Email: laura.lehman@childrens.harvard.edu

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CLINICAL PERSPECTIVE

What Is New?

- Children with pediatric intracerebral hemorrhage often experience maladaptive neurologic, cognitive, behavioral, and socioemotional outcomes that can affect their learning and academic progress, social development, and independence in daily living.
- Key determinants for predicting outcomes in pediatric intracerebral hemorrhage include medical, demographic, familial, and socioeconomic factors.

What Are the Clinical Implications?

- Neurological examination and comprehensive neuropsychological assessment are critical first steps in planning interventions and should be a routine part of outcome evaluation to ensure timely intervention and consequently improved neurological function (eg, motor, visual), learning, academic achievement, emotional adjustment, and development of independence.

Nonstandard Abbreviations and Acronyms

ABI	acquired brain injury
AIS	arterial ischemic stroke
HS	hemorrhagic stroke
pICH	pediatric intracerebral hemorrhage

(HS) is much more limited even though it comprises >50% of childhood strokes[1] and ranks among the top 10 causes of pediatric deaths.[2] HS consists of intracerebral hemorrhage (ICH), defined as nontraumatic intraparenchymal hemorrhage with or without intraventricular bleed, and subarachnoid hemorrhage. In this consensus statement, we focus primarily on pediatric intracerebral hemorrhage (pICH) and state where the limited outcomes data also included other types of HS.

The field of pediatric HS has shifted its focus from survival to survivorship, including monitoring for challenges and focusing on appropriate supports, rather than just describing the neurological sequelae in more general terms, such as *good* or *poor*.[3,4] This shift has led to local, national, and international interdisciplinary initiatives to address knowledge gaps related to pICH outcomes in children.[1] Although death after pICH is lower than in adults,[5] it remains significant compared with childhood AIS or even compared with the burden of pediatric diseases overall.[2,3,6,7] There are important differences in the initial provision of care between hemorrhagic and ischemic strokes including the involvement of different interdisciplinary teams. Specifically, children with pICH frequently require neurosurgical or interventional neuroradiological management in addition to neurocritical care. Since pICH encompasses a heterogeneous group of conditions manifesting across a broad developmental range, from infancy to adolescence, studying outcomes remains complex. This challenge necessitates an adaptive approach, including long-term assessment in multiple domains with age-related adjustments. The chronic care continuum includes a wide range of interdisciplinary patient- and family-centered approaches such as rehabilitation therapies, neuropsychology, and behavioral therapies to support the optimization of outcome and development. This comprehensive focus on long-term outcomes highlights the need for further coordinated research and quality improvement in this field.

To date, HS-specific reports of long-term outcomes are scarce and even less studied in pICH alone. Studies are retrospective, cross-sectional, and based on small samples,[8–10] with data often derived from heterogeneous HS populations. Furthermore, they also frequently combine several conditions (eg, AIS, HS, or more broadly all types of acquired brain injury [ABI]), and often define the HS population with notable variability [eg, intracerebral hemorrhage, subdural and subarachnoid bleeds; or ruptured and unruptured arteriovenous malformation [AVM]). Thus, reliable evidence-based neuroprognostication remains challenging.

Here, members of the Hemorrhagic Stroke Working Group of the International Pediatric Stroke Organization present a summary of the limited available data on motor, cognitive, emotional, and adaptive outcomes following pICH. While all referenced studies were focused on pICH, due to the paucity of published data, some also included other types of hemorrhage (eg, subarachnoid). We propose general guidelines regarding interventions aimed at children and adolescents with ABI, including stroke, as these apply to HS/pICH as well. Finally, we provide guidance for measuring outcomes in both clinical practice and research settings.

NEUROLOGIC, MOTOR AND GLOBAL FUNCTIONAL OUTCOMES

Although improvement has been reported over the first year following pICH,[11] most children (≈75%) have persistent neurological deficits. One of the largest HS outcome studies (the majority with pICH) found that up to 48% of children with HS occurring between ages 1 and 20 years had no long-term motor impairment, but hemiparesis was the most frequent pattern of weakness in those with motor impairment (≈36%).[12] Another outcome

study including 106 children with ruptured AVM measured clinical outcomes using the King Outcome Scale for Childhood Head Injury; 76% had a good outcome, 13% had mild disability, 4% had a severe disability, 2% remained in a persistent vegetative state, and 5% did not survive.[13] Risk factors for unfavorable outcomes included volume of intracranial hemorrhage (≥30 cm^3) and development of hydrocephalus.[13] The significant uncertainties and potential for ongoing recovery are important to consider when planning care and discussing neuroprognostication with families.

A retrospective study from a pediatric rehabilitation center reported better motor and functional outcomes in children admitted for acute rehabilitation after HS (n=82) compared with those after AIS (n=46).[14] The HS patients in this cohort all had pICH (the large majority from ruptured AVM, 4 from ruptured cavernoma, 5 from ruptured aneurysm, and 5 with "unexplained" pICH) (author personal communication). Even though impaired adaptive skills are seen in about half of pediatric HS survivors, most children reach at least some level of functional independence in activities of daily living.[12,15,16]

COGNITIVE, BEHAVIORAL, AND SOCIOEMOTIONAL OUTCOMES

About half of children with HS experience cognitive and adaptive deficits,[12,15,16] impeding their academic and vocational outcomes. In a study of 34 children with spontaneous intracerebral hemorrhage, even those with seemingly "good recovery" on global outcome scales experienced cognitive and behavioral problems.[17] Memory and attention difficulties are common and reported in up to 45% of survivors of pediatric pICH.[17,18] Murphy et al found longitudinal improvement in some higher-order intellectual function and overall neurologic function in 7 children with pICH.[11] In contrast, cognitive proficiency (eg, processing speed, working memory) was impaired and showed a further decline over time, suggesting these children were not progressing in an age-expected manner in all aspects of executive functions.[11] Children with ruptured AVMs performed poorly on language-based measures of working memory, verbal fluency, and aphasia screening; their performance was worse than that seen in patients with severe traumatic brain injury,[19] implying more diffuse brain injury than initially apparent. A recent large rehabilitation center–based retrospective study including a mixed sample of 79 children with AIS and 105 with HS (the large majority with pICH due to AVM) found overall intellectual ability falling in the low average range.[20] Moreover, up to 53% of children exhibited impairments in formal language assessment of lexical and syntactic expression, as well as comprehension.[20] School function was strongly associated with performance on language and intellectual assessments. The authors further reported that after >3 years of median follow-up, only 27% of children did not require any educational support, while another 27% needed special education over time.[20] No significant differences in intellectual ability between AIS and HS were found in a subsample of 128 children from the same cohort, which included 82 children with HS (the large majority with pICH).[14]

Most HS survivors experience low self-esteem, and emotional and behavioral problems, even years after the injury.[12,21] In a case series of 5 children with ruptured AVMs, adaptive functions remained below age expectation, and parents frequently identified concerns in their child's social skills despite seemingly good initial adjustment.[22] In contrast, a longitudinal study of 29 children with ruptured and unruptured AVMs demonstrated "favorable" outcomes in social functioning, with most returning to school or work settings, despite persistent cognitive difficulties.[18]

ACADEMIC/RETURN TO SCHOOL

Impaired academic performance after childhood HS is commonly observed as a consequence of a combination of motor, cognitive, behavioral, and adaptive deficits. While most children return to school within a year, more than half require adaptations, additional support or special educational interventions in the long term.[14,23] In one study of patients with pICH, persistent motor deficits as measured by the Pediatric Stroke Outcome Measure at 3 and 12 months after stroke accurately predicted the need for educational support.[23] However, another study of mixed types of HS (mostly pICH) found that when outcomes were adjusted for general intellectual function, intellectual function remained the only robust significant predictor of the need for special education services in the long term.[14]

TRANSITION TO ADULTHOOD

Very little research is available on how children with HS, or pICH specifically, function over time as they progress into adulthood. A long-term follow-up study of 29 young adults with a history of either childhood ischemic stroke (2/3) or HS (1/3) found that 88% of survivors of stroke graduated from high school, although 45% required special education, and 64% of those aged >18 years were attending college. Furthermore, 79% of those aged >16 years were driving, and 60% were employed. In contrast, only 28% of those aged 18 years were living independently, away from their parents, and only 2 young adults in the cohort were financially independent. Mobility outcomes were overall good, while functioning

fell in the low to moderate range for communication, activities of daily living, and socialization.[24] For comparison, a recent study reporting long-term outcomes for survivors of pediatric AIS reported impairments in executive functioning and work productivity, yet no differences in quality of life, depression, or fatigue compared with healthy controls.[25] However, some studies suggest that mood problems can persist into adulthood and impact long-term outcomes and independence. One report described mood problems, such as depression and anxiety requiring treatment in more than a quarter of young adult survivors of AIS, despite independence in driving, relationships, and employment for most patients.[26]

DETERMINANTS OF OUTCOME AND NEUROPROGNOSTICATION

Limited evidence suggests that predictors of adverse outcomes following pICH include the severity of presenting symptoms (including decreased Glasgow Coma Scale score on admission), length of coma, volume of hemorrhage, infratentorial location of hemorrhage, presence of an aneurysm, need for neurosurgical intervention, rebleeding, length of stay in the pediatric intensive care unit, neurosurgical complications leading to increased intracranial pressure and the development of acute hydrocephalus.[8–10,27–29] The presence of coagulopathy and underlying hematological disease has also been associated with worse outcomes.[17,30,31] In another study, the rate of recovery of sensorimotor function after the acute phase was the best predictor of favorable outcome.[9]

Younger age at the time of the brain injury is associated with worse outcomes in some[17,20] but not all studies.[30,31] This discrepancy could be a result of variations in sample size, type of outcomes measured, and timing of the follow-up assessment. Specifically, younger age at time of stroke has been associated with poorer cognitive outcomes, a finding well established in childhood AIS.[32] Complex cognitive and socio-emotional functions develop over time, and therefore deficits in these domains may not become apparent until children are expected to meet developmental milestones through the school and social settings.

Personal, family, and environmental factors, such as lower premorbid functioning, lower socioeconomic status, and poorer parental mental health and family functioning, have been consistently associated with worse outcomes in childhood ABIs,[33] and some studies have confirmed these findings for pediatric stroke as well,[34–36] although data specifically for pICH remain limited.[37]

Regarding poststroke factors affecting outcome, epilepsy is known to have an adverse impact on outcomes after brain injury. This was specifically shown to be true in a mixed cohort of children with pICH, AIS, and perinatal stroke studied for cognitive and academic outcomes, which can in turn significantly impact the long-term quality of life.[38] Another study including 53 pediatric survivors of intracerebral hemorrhage from 3 tertiary centers across the United States found that a single remote symptomatic seizure occurred in 23% of survivors of pICH, and epilepsy developed in 13%, all within 2 years after the pICH.[39] The risk of remote symptomatic epilepsy was higher in survivors requiring surgical intervention for elevated intracranial pressure.[39]

As in other types of brain injury, neuroprognostication should be multimodal, combining information collected from neuroimaging, electroencephalography, and comprehensive multidisciplinary clinical exam. Key factors to consider include premorbid state, age at injury, laterality of injury, recurrent bleeds, and presence of an additional global insult or secondary brain injury. Despite high variability in outcomes, serial assessments (radiologic, neurologic, neuropsychological), adequately timed and tailored to the patient's progress, can help to improve the accuracy of short- and long-term prognostication.

REHABILITATION

The evidence base supporting improved outcomes with rehabilitation for pediatric HS is limited. Most available data stem from studies in AIS for motor rehabilitation (eg, constraint-induced movement therapy, hand–arm intensive bimanual training), and from traumatic brain injury/ABI (including HS) for cognitive/behavioral interventions (eg, attention/working memory training, behavior modification, family-focused interventions).[40,41] For many of these interventions, however, the data only show small to moderate effects in the near term and limited long-term and generalizable effects. Therefore, several clinical consensus guidelines have been developed globally to apply more general, integrative approaches.[42–44]

Limited evidence suggests that effective rehabilitation extends beyond current evidence-based training of function and includes compensatory strategies, environmental adaptation, and education of families and schools regarding childhood stroke outcomes. Guidelines now recommend (1) to include caregivers/educators and allied health professionals in rehabilitation; (2) to repeat neuropsychological assessments to capture changing developmental needs; and (3) to individually tailor interventions that foster *everyday* function. In the acute phase, initial rehabilitation is often multidisciplinary and hospital based. Adequate discharge planning is crucial and should include key family members and identified professionals from health, education, and psychosocial care to support rehabilitation and reintegration into

the home and school life. Assessments and interventions should consider core domains of the *International Classification of Functioning, Disability and Health: Child and Youth Version of the World Health Organization* (*ICF-CY*, 2007) and take child and family priorities and preferences into account. Interventions should be goal-oriented and adapted to individual and environmental factors (eg, developmental abilities, social, family, and educational demands).[45]

Common interventions include medications for symptom management (eg, anticonvulsants, mood stabilizers, botulinum toxin, baclofen); motor therapy (eg, occupational and physical therapy, constraint-induced movement therapy, bimanual training, serial casting, bracing, mobility and strength training; speech/language therapy (motor–speech, aphasia); educational interventions for cognitive and academic weaknesses (eg, tutoring/special educational instruction, classroom and test accommodations such as extended time, modified materials and curriculum); and psychological interventions for behavioral or socioemotional problems (eg, behavior therapy, counseling). Although limited, available studies on motor interventions in the acute and subacute phases indicate improvement in functional recovery.[46]

A central focus in "rehabilitation" after childhood stroke is the child's reintegration into age-appropriate environments (academic, social, family), and foremost return to school. Many children (up to 50%) require adaptations or special educational services after HS, often long term.[23] Thus, serial neuropsychological and rehabilitative assessments are important to monitor the child's overall cognitive development, independence, as well as learning and social integration, and identify needs as they arise, especially at major transition points (eg, entering school, moving to secondary school, transition to the workforce). This should occur regularly until the transition to adult services.[44,47] These assessments allow accurate determination of the current functional status in the context of the environment and collaborative intervention planning (medical, therapeutic, educational) according to the patient's and family's goals.

MEASURING OUTCOME

Currently, no validated outcome instruments exist specifically for HS. Measures for global outcome have been validated only in AIS (eg, Pediatric Stroke Outcome Measure, Pediatric National Institutes of Health Stroke Scale). Assessment of more specific functional domains is highly dependent on several factors including the child's age, development, level of impairment, the aims of the assessment (eg, initial assessment to inform rehabilitation, subsequent comprehensive neuropsychological assessment to inform school reentry), the outcome measures available in a country or language, and the clinician's judgment and observation (eg, need for adapted assessment in case of motor, visual, and speech impairments). Within this context, most "toolkits" rely on measures that may have been previously used in studies of stroke, regardless of their reliability and validity in a specific population or context (eg, short versus long term, single time point versus repeated testing, specific function studied). Therefore, "prescribing" a battery of specific measures/tools remains difficult; the appropriate tools vary largely on the basis of the outcome studied, age/developmental stage, and country (eg, measures developed in US populations with US reference norms are not generalizable to other countries).

To assess long-term outcomes in both the research and clinical context where variability in development and outcomes makes a uniform approach challenging, the following principles are suggested:

1. Longitudinal, repeated neuropsychological assessments and neurological examination. Close follow-up is needed to respond to clinical concerns, monitor skill development over time, and individualize SMART (specific, measurable, achievable, realistic, time-bound) goal-oriented interventions and supports provided during "critical windows" of development, including times of transition (ie, start of kindergarten, middle school, high school, college).
2. Use of norm-referenced measures for specific domains of study.
3. Use of "hallmark" measures most commonly administered for each domain to allow cross-comparison (see Table [48–147] for specific examples by domain of outcome).
4. Prospectively ascertained outcomes are preferred over retrospective ones in the research setting.
5. Implementation of longitudinal (repeated) over cross-sectional (single time point) protocols, with relevant long term follow-up (ie, every 2 years and at transition points) including long-term monitoring following patients into adulthood.
6. Clear HS definition and prospective follow-up of all patients with HS to avoid bias introduced by clinically referred samples.

KNOWLEDGE GAPS, IMPORTANT NEEDS, AND FUTURE DIRECTIONS

Despite an increasing body of literature on neurologic, cognitive, behavioral, and adaptive outcomes after

Table Specific Examples of Measures by Domain of Outcome.

Functional domain	Subdomain	Example measures*	Age range†	Method	Informant	Norms available
Global outcome	Overall level of disability severity Functional impairment	Functional Status Scale[48]	0–16	Rating scale–inpatient	Physician or trained health professional	No
		Hammersmith Infant Neurological Examination[49–53]	3–24 mo	Rating scale	Physician or trained health professional	No
		King's Outcome Scale for Childhood Head Injury[54,55]	2–16	Rating scale	Physician or trained health professional	No
		Modified Rankin Scale[56]	0–18	Rating scale	Physician or trained health professional	No
		Pediatric Cerebral Performance Category/ Pediatric Overall Performance Category[57–59]	0–18	Rating scale	Physician or trained health professional Medical records or caretaker's information can be used	No
		Glasgow Outcome Scale Pediatric Version (Adapted version of Glasgow Outcome Scale)[60,61]	0–18	Rating scale	Physician or trained health professional	No
		Pediatric Stroke Outcome Measure[62–66]	0–2, 2–18	Rating scale	Neurologist or trained health professional	Age norms
		Pediatric Stroke Recurrence and Recovery Questionnaire[67]	0–18	Rating scale	Parent, child	No
		Pediatric Functional Independence Measure	6 months – 7 years	Performance scale	Trained professional or parent or both	Age norms
Motor function	Gross motor	Action Research Arm Test[68]	13–18	Rating scale	Trained health professional	No
		Assisting Hand Assessment[69,70]/Hand Assessment for Infants/Mini-Assisting Hand Assessment[71]	18 mo–18 y/8–18 months (Mini- Assisting Hand Assessment)	Criterion reference test	Trained and certified health professional	Age norms
		Bruininks–Oseretsky Test of Motor Proficiency[72]	4–21	Performance measure, age-based standard scores	Trained health or research professional	Norm referenced
		Community Mobility and Balance Test[73–77]	13–adulthood	Rating scale	Trained health professionals	No
		Fugl–Meyer[78–82]	13–17	Scoring based on direct observation of performance	Trained physical therapist, occupational therapist or rehabilitation professional	No
		Gross Motor Functional Measure[83–85]	5 mo–16 y	Rating scale, criterion reference observational assessment	Trained pediatric therapists	No
		6-Minute Walk Test[86–88]	2–5 6–12 13–18	Rating scale	Trained health or research professionals	Age norms
	Oromotor	Dysphagia Disorder Survey[89–91]	18–24 mo 2–adulthood	Task analysis tool, rating scale	Caregiver, trained health professionals	Age norms
	Fine motor	Test of Arm Selective Control[92]	4–adolescence	Rating scale	Trained pediatric therapists	No
		Quality of Upper Extremity Skills Test[93–95]	18 mo–18 y	Performance measure, rating scale	Trained health professionals	No
		Mini-Manual Ability Classification System[96,97]	1–4 4–18	Rating scale	Trained health professionals	Age norms
		Melbourne Assessment of Upper Limb Function[98]	2.5–15	Rating scale	Trained health or research professionals	Age norms (from >4 y)
		Pediatric Arm Function Test[99]	2–6	Rating scale	Trained health or research professionals	No
		Pediatric Balance Scale (modified from the Berg Balance Scale)[77]	5–15	Rating scale	Trained health or research professionals	No
		Pediatric Neuromuscular Recovery Scale[100]	1–12	Rating scale	Trained pediatric health professionals	No
General cognitive	Cognitive, language, motor development	Bayley Scales of Infant and Toddler Development (Bayley-III)[101,102]	1–42 mo	Standardized test	Psychologist/Psychometrist	Age norms
	Intellectual ability	Wechsler Intelligence Scales (WPPSI-IV, WISC-V, WAIS-IV, WASI-II)[103–109]	3–7, 6–16;11, 16+	Standardized test	Psychologist/Psychometrist	Age norms

(*Continued*)

Table. (Continued)

Functional domain	Subdomain	Example measures*	Age range†	Method	Informant	Norms available
Executive/ Attention	Attention Processing speed Working memory Planning Organization Monitoring Behavior regulation	Developmental Neuropsychological Assessment (NEPSY-II)[110,111] Delis–Kaplan Executive Function System[112,113]	3–4, 5–16 8–99	Standardized test	Psychologist/Psychometrist	Age norms
		Conners' Continuous Performance Test-3,[114] Test of Everyday Attention[115]	5–15	Standardized test	Psychologist/Psychometrist	Age norms
		NIH Toolbox Cognition[116]	3–6, 7+	Standardized research tasks	Psychometrist/Trained research staff	Age, educational
		Behavior Rating Inventory of Executive Functions (BRIEF-2/Preschool/Adult)[117,118]	3–5, 5–18, 18+	Rating scale	Parent, child	Age norms
Memory	Verbal Visual Spatial	Children's Memory Scale[119]	5–16	Standardized test	Psychologist/Psychometrist	Age norms
		Wechsler Memory Scale (WMS-IV)[120]	16–90	Standardized test	Psychologist/Psychometrist	Age norms
		California Verbal Learning Test (CVLT-Children's Version/CVLT-3)[121,122]	5–16, 16+	Standardized test	Psychologist/Psychometrist	Age norms
		Rey-Osterrieth Complex Figure (ROCFT)[123,124]	5–14, 6–89	Standardized test	Psychologist/Psychometrist	Age norms
Visual–spatial	Visual-motor Visual planning Spatial orientation Perceptual organization	Beery-Buktenica Developmental Test of Visual-Motor Integration (VMI-6)[125]	2–99	Standardized test	Psychologist/Psychometrist	Age norms
		Judgment of Line Orientation[126]	7–74	Standardized test	Psychologist/Psychometrist	Age norms
		Rey-Osterrieth Complex Figure (ROCFT)[123,124]	5–14; 6–89	Standardized test	Psychologist/Psychometrist	Age norms
Language	Word retrieval Expressive language Receptive language Language formulation	Children's Acquired Aphasia Screening Test[127]	3–7	Standardized test	Psychologist/Psychometrist	Age norms
		Boston Naming Test[128]	6+	Standardized test	Psychologist/Psychometrist	Age norms
		Expressive One-Word Picture Vocabulary Test[129]	2–70+	Standardized test	Psychologist/Psychometrist	Age norms
		Receptive One-Word Picture Vocabulary Test[130]	2–70+	Standardized test	Psychologist/Psychometrist	Age norms
		Clinical Evaluation of Language Fundamentals (CELF-5)[131]	5–21	Standardized test	Psychologist/Psychometrist	Age norms
Behavior	Broadbend: Externalizing Internalizing Adaptive	Behavior Assessment System for Children (BASC-3)[132]	2–21 6–25	Rating scale	Parent, teacher child self-report	Age norms
		Achenbach Child Behavior Checklist/Youth Self-Report (CBCL/YSR)[133,134]	1.5–5, 6–18 11–18	Rating scale	Parent, teacher youth self-report	Age norms
	Attention Hyperactivity	Vanderbilt ADHD Diagnostic Rating Scale[135]	6–12	Rating scale	Parent, teacher	No
Specific Mood	Depression	Children's Depression Inventory (CDI-2)[136]/ Beck Depression Inventory (BDI-II)[137]	7–17 13–80	Rating scale	Child self-report, parent	Age norms
	Anxiety	Multidimensional Anxiety Scale for Children (MASC-2)[138,139]	8–19	Rating scale	Child self-report, parent	Age norms
		NIH PROMIS measures[140–142]	1–5, 5–17 8–17, 18+	Rating scale	Parent Child self-report	Age norms
Adaptive		Adaptive Behavior Assessment System (ABAS-3)[143] Vineland Adaptive Behavior Scales (Vineland-3)[144]	0–89; 0–5, 5–21 0–90, 3–18	Rating scale/interview	Parent, teacher	Age norms
		Ages and Stages Questionnaire (ASQ-3)[145]	0–6	Rating scale	Parent	Age norms
		Pediatric Quality of Life Inventory Generic Core Scales and Cerebral Palsy Module[146,147]	2–18	Rating scale	Parent/child	No

ADHD indicates attention deficit/hyperactivity disorder; NIH, National Institutes of Health; PROMIS, Patient-Reported Outcomes Measurement Information System; WAIS-IV, Wechsler Adult Intelligence Scale, Fourth Edition; WASI-II, Wechsler Abbreviated Scale of Intelligence, Second Edition; WISC-V, Wechsler Intelligence Scale for Children, Fifth Edition; and WPPSI-IV, Wechsler Preschool and Primary Scale of Intelligence, Fourth Edition.

*The listed instruments represent example measures commonly used in the United States and Canada yet are not meant as an exhaustive list of available measures in North America or globally. For specific batteries see the NIH Common Data Elements for Traumatic Brain Injury and Stroke.

†If not otherwise specified, age is listed in years.

pediatric HS, there remain important knowledge gaps and needs for future research and clinical care to overcome them. These include the following:

1. Inconsistencies in published data within HS and between HS and AIS highlight the need for larger and longitudinal studies with more

homogenous HS samples to understand the immediate functional outcomes in this population and their long-term neurodevelopmental needs.
2. Neurological examination and comprehensive neuropsychological assessment are critical first steps in planning interventions and should be a routine part of outcome evaluation to ensure timely intervention and consequently improved neurological function (eg, motor, visual), learning, academic achievement, emotional adjustment, and development of independence.[17]
3. Service models and research that address the transition to adulthood and advise on topics such as reproductive health (eg, contraception, pregnancy, labor) and potential restrictions (eg, sports, activities) are urgently needed to inform care. Outcome prediction should account for global/diffuse injury secondary to complications associated with pICH versus focal brain injuries related to pICH.[19]
4. Standardization of timing and duration of follow-up as well as a minimal data set with clearly defined outcomes is required to better understand rehabilitation and learning needs.
5. Research on prognostic factors needs to include assessment of social determinants of health, which has been shown to have similar if not larger predictive power for cognitive and behavioral outcomes.
6. This also should include preinjury functional (cognitive, behavioral, academic) status as a potential contributor for poststroke outcome.
7. Multicenter research is needed to provide larger samples and comparisons across samples and across HS versus AIS populations to determine potential commonalities or differences in functional outcome, immediately and long term.

In conclusion, given that pediatric HS is a rare condition, large studies on specific and general outcomes (including participation, quality of life, and specific interventions) are needed. Many lessons can be learned from current knowledge and practices in childhood ABI (including AIS), and some clear and practical recommendations are available for informing clinical practice. Neuroprotection measures in the acute phase can be planned based on already identified prognostic factors as well as general interventions for acute ABI. However, multicenter, collaborative research on HS outcomes would be beneficial, similar to those successfully developed and implemented for childhood traumatic brain injury/ABI or brain tumors. Multisite, ideally international, HS registries such as the ones developed by the International Pediatric Stroke Study, the research arm of the International Pediatric Stroke Organization, will provide especially useful vehicles to answer these important questions.

ARTICLE INFORMATION

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Affiliations

Department of Psychiatry (C.M.) and Department of Neurology (C.M., L.L.L.), Boston Children's Hospital, Harvard Medical School, Boston, MA; Division of Pediatric Neurology, Department of Pediatrics, University of Alberta, Edmonton, Alberta, Canada (J.A.M.); Rehabilitation Department for Children with Acquired Neurological Injury, Saint Maurice Hospitals, Saint Maurice, France (M.C.); Sorbonne Université, INSERM, CNRS, Laboratoire d'Imagerie Biomédicale, LIB, Paris, France (M.C.); Division of Neurology, The Hospital for Sick Children, Toronto, Canada (N.D.); Departments of Neurology and Pediatrics, University of California San Francisco, San Francisco, CA (C.K.F., H.J.F.); Diagnostic and Interventional Neuroradiology, CIC-IT 1415, CHRU de Tours, INSERM 1253 iBrain, Centre Val de Loire, Tours, France (G.B.); France National Reference Center for Pediatric Stroke, Paris, France (G.B.); and Queensland Children's Hospital Paediatric Intensive Care Unit, South Brisbane, QLD, Australia (M.W.).

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