SPECIAL ARTICLE

Quality improvement in neurology: Child neurology quality measure set

Executive summary

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Neurology® 2018;90:67-73. doi:10.1212/WNL.0000000000004806

Childhood neurologic disorders, as a group, include relatively common conditions such as migraine (prevalence between 3% and 10.6% in children 3–15 years of age[1,2]), transient tic disorders (TDs) (3%),[3] and specifically Tourette syndrome (TS) (0.8%),[3] and rarer disorders such as infantile spasms that may occur in only about 1,200 infants each year in the United States. These disorders account for a disproportionately higher number of emergency department visits, intensive care admissions, deaths, and higher costs when compared to other childhood illness.[4] Generally, delivery of quality care should improve outcomes and result in decreased unnecessary utilization of health services.[4]

Transition from pediatric to adult care is a focus of the American Academy of Pediatrics and other organizations.[5] The issues surrounding transition for adolescents with chronic illness cannot all be addressed at the primary care level and need to be addressed in specialty care. Due to these factors, quality measures are needed and represent a current gap in this field.

In 2016, the American Academy of Neurology (AAN) and Child Neurology Society (CNS) formed the Child Neurology Work Group to review existing guidelines, current evidence, and gaps in care. The goal of this Work Group was to develop a measurement set for child neurology that promotes quality improvement and drives better outcomes for neurologically ill children. Quality measures are not guidelines. Quality measures use guidelines and other best practices to assess and document performance of quality care to promote practice improvement when gaps in care exist. Quality measures use current guidelines, consensus statements, and other standards.

The AAN and CNS developed these quality measures based on the belief that specialists should play a major role in selecting and creating measures that will drive improvement and possibly be used in accountability programs. The AAN and CNS formed the Work Group with representatives from professional associations and patient advocacy organizations to ensure input from a diverse set of members of the health care team.

In this executive summary, we report on the quality measurement set developed by the Work Group (table). The full measurement set, including specifications, is available online (http://links.lww.com/WNL/A83).

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Dr. Adam Numis interviews Dr. Jeffrey Buchhalter and Dr. Anup Patel about their paper, a quality measure set executive summary on child neurology.
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Go to Neurology.org/N for full disclosures. Funding information and disclosures deemed relevant by the authors, if any, are provided at the end of the article.

Approved by the AAN Quality and Safety Subcommittee on December 22, 2016; the AAN Practice Committee on December 28, 2016; the Child Neurology Board of Directors on January 9, 2017; and the AANI Board of Directors on January 3, 2017.

Glossary

AAN = American Academy of Neurology; **ACTH** = adrenocorticotropic hormone; **CDH** = chronic daily headache; **CMA** = chromosomal microarray; **CNS** = Child Neurology Society; **GDD** = global developmental delay; **IS** = infantile spasms; **SE** = status epilepticus; **TD** = tic disorder; **TS** = Tourette syndrome.

Supplemental Data
Full measurement set at
NPub.org/vwx8qf

Opportunities for improvement

Child neurology focuses on pediatric diseases across the neurologic spectrum. Opportunities for quality improvement were identified for a variety of neurologic conditions. Review of the literature revealed gaps in care and areas where quality measures might be used to drive improvement in care. This measurement set focuses on a subset of neurologic illness seen in the pediatric population.

Infantile spasms

Infantile spasms (IS) is a potentially devastating early-life electroclinical syndrome that can lead to developmental regression, intellectual disability, and lifelong epilepsy.[6–11] The prevalence of IS ranges from 2 to 3.5 per 10,000 live births per year and is often accompanied by neurodevelopmental regression and hypsarrhythmia on EEG recording.[12–14] Successful early treatment can protect ongoing development and lead to permanent remission. First-line treatments include adrenocorticotropic hormone (ACTH), high-dose prednisolone, and vigabatrin. Numerous studies have documented delays in use of, inadequate, or inappropriate treatment,[15] despite evidence from randomized trials, an AAN practice parameter, and other consensus statements. Delayed diagnosis and treatment can result in lasting deleterious deficits in development and cognition.

Status epilepticus

Status epilepticus (SE) is a neurologic emergency characterized by unremitting seizures or seizures that recur without return to baseline mental status. Estimates indicate 50,000 to 150,000 people in the United States have an episode of SE each year.[16] SE can be convulsive (e.g., seizures with tonic, tonic-clonic, or clonic features) or nonconvulsive (e.g., absence status). As convulsive SE is associated with higher morbidity and mortality, it has been the focus of guidelines for evaluation and management. The most recent guideline defines SE in children as any clinical or electrographic seizure lasting longer than 5 minutes.[16,17] This guideline was designed to lead to a substantial reduction in morbidity and mortality associated with SE.

TS and TD

TDs, including TS, are the most commonly diagnosed movement disorders in childhood, with prevalence rates

Table 2016 Child neurology measurement set

Clinical problem	Measure description
Infantile spasms	Percentage of patients receiving appropriate first-line treatment for infantile spasms
Epilepsy	Percentage of patients who received appropriately and correctly dosed rescue seizure therapy for children with epilepsy
Refractory convulsive status epilepticus	Percentage of patients who received the start of a third-line therapy for seizure cessation for refractory convulsive status epilepticus
Epilepsy	Percentage of patients with epilepsy screened for neurodevelopmental or neuropsychological deficits
Tic disorder and Tourette syndrome	Percentage of patients who were queried for psychological or behavioral comorbid conditions of tic disorder or Tourette syndrome
Tic disorder or Tourette syndrome	Percentage of patients who were treated or referred for treatment for comorbid symptoms of tic disorder or Tourette syndrome
Tic disorder or Tourette syndrome	Percentage of patients who were counseled or referred for behavioral therapy for management of chronic tic disorder or Tourette syndrome
Global developmental delay	Percentage of patients who had genetic testing ordered for global developmental delay
Chronic headache	Percentage of patients who have been counseled to seek psychological or biobehavioral interventions for management of chronic headache
Spasticity or dystonia	Percentage of patients with spasticity or dystonia who were evaluated or referred or treated with botulinum toxin A
Transition to adult neurology care	Percentage of patients who had a neurologic transition plan of care

estimated between 0.3% and 1% of the population.[18,19] They occur more frequently in boys than girls and are characterized by repetitive, stereotyped involuntary movements and vocalizations.[18–20] TDs often resolve in childhood, but may persist into later adult life.[20] TS and TDs are associated with psychiatric conditions such as attention-deficit/hyperactivity disorder, obsessive-compulsive disorder, oppositional defiant disorder, and mood disorders including depression and anxiety. Intervention for these comorbidities can lead to substantial functional improvements in this population, but the rate at which screening occurs for these conditions is unknown. In addition, effective behavioral interventions to reduce the frequency of tics and improve quality of life are likely underutilized.

Headache and migraine

Headache, in particular migraine, is a common pediatric problem worldwide, and it can become a chronic and disabling disorder.[21] Overall, 6.0% of children are at risk for headache in their lifetime, with female patients being affected at a greater rate than male patients.[21] The prevalence for migraine for those under 20 years of age is 7.7%.[21] Headaches can become very frequent and evolve into chronic daily headache (CDH), a clinical syndrome that continues to be used frequently and defined as "pain localized to the head occurring 15 or more days per month for more than 3 months."[22] Chronic migraine, a form of CDH, is estimated to occur in up to 1.8% of adolescents aged 12–17 years.[23] While there are many pharmacologic treatments available for migraine and other primary headache disorders, pediatric clinical trials, including the recent Children and Adolescent Migraine Prevention (CHAMP) study, consistently show high placebo response rates, highlighting the psychological aspects of the disorder that can be addressed by nonpharmacologic strategies. Cognitive-behavioral therapy when combined with amitriptyline has shown to be more effective in reducing headache frequency and migraine-related disability among youth aged 10–17 years.[24] Nonpharmacologic treatment of headache, such as psychological interventions, have been shown to be as effective as first-line therapy, but the frequency of adoption of this as first-line therapy in clinical practice is unknown.[25]

Cerebral palsy

Cerebral palsy represents a group of nonprogressive disorders due to brain injury that affect postural and motor control resulting in activity limitations.[26] Estimates from the CDC suggest an incidence of 3.3 per 1,000 live births per CDC data.[27] Reduction of spasticity and dystonia can result in increased mobility and decreased pain. Medical treatments for spasticity and dystonia include oral medications or IM injections of botulinum toxin. Surgical treatments include surgical placement of an intrathecal baclofen pump, deep brain stimulator, and selective dorsal rhizotomy. Measures to improve functioning include physical, occupational, and speech therapies as well as the use of orthoses and adaptive equipment.[28]

Global developmental delay

Global developmental delay (GDD) is diagnosed in children with significant delay in acquiring early childhood developmental milestones in more than 2 domains: motor, speech and language, cognitive, and social/adaptive behavior.[29] The diagnosis is not synonymous with intellectual disability and puts a child at risk for long-term cognitive impairments and functional dependence. In children without autism, between 1% and 3% meet criteria for GDD.[29] Approximately 40% of otherwise unexplained GDD is due to genetic and metabolic disorders rather than environmental factors.[30,31] Genetic testing that establishes a specific diagnosis has a number of benefits for patients and families and can result in important changes in management.[32]

Transition to adult neurology

The shortage of pediatric neurology providers and increasing number of pediatric neurology patients limits the ability of the health care system to retain adult patients in the pediatric system.[33] As patients age, they have concomitant health problems that are more commonly seen in the adult population. The transition of adolescents with chronic neurologic disorders from a pediatric to an adult neurologist seems to be a sensible solution, though it is a significant challenge.[34,35] Young people referred to adult practitioners from tertiary pediatric centers have more complex health problems. Adult providers report lower levels of confidence in caring for these patients.[36] Other barriers to the transition to adult care are the adolescent and family anxiety of leaving familiar care, which is often family-centered. The adult setting is not always equipped to handle intellectual disabilities and difficult behavior, which is more common in patients with chronic neurologic conditions of pediatric onset.[33] The American Academy of Pediatrics has outlined a formal transition process to address the gaps that currently exist in practice.[37] A transition plan is essential in ensuring that this occurs.

Methods

The AAN and CNS formed a cross-specialty and multidisciplinary expert Work Group of diverse key stakeholders from physician and nonphysician associations, patient and caregiver advocacy organizations, and payers. Details of the full measure development process are available online.[38] The formation of the Work Group began with a nomination process from AAN and CNS. The co-chairs and facilitators selected members from the pool of qualified specialists and expert nominees. The selection was based on the nominees' experience in quality measures, quality improvement, and clinical activities. The final Work Group (23) included physicians, advanced practice providers, physical therapists, and a parent advocate (listed at the end of the manuscript).

Initially, Work Group members disclosed potential conflicts of interest and completed applications summarizing experiences and interests. Work Group members were selected

based on experience in various disciplines of child neurology, quality improvement, and quality measurement.

The measure development process included the following: (1) evidence-based literature search, (2) establishing a multidisciplinary Work Group adhering to the AAN conflict of interest policy, (3) drafting candidate measures and technical specifications, (4) convening the Work Group in person to review candidate measures, (5) refining and discussing the candidate measures, (6) soliciting public comments on approved measures during a 30-day period, (7) refining the final measures according to input received during the public comment period and corresponding technical specifications, and (8) obtaining approvals from the Work Group, AAN Quality and Safety Subcommittee, AAN Practice Committee, AAN Institute Board of Directors, and CNS Board of Directors.

The Work Group sought to develop evidence-based measures to support the delivery of high-quality care and to improve patient outcomes. The co-chairs and facilitators, guided by a medical librarian, conducted a comprehensive literature search identifying 7,840 abstracts relevant to the potential measures including 22 clinical practice guidelines. Following the development of draft measure concepts during the in-person meeting, a public comment period resulted in over 300 comments from 60 individuals, which drove concept refinement.

The AAN and CNS plan to provide resources to update these measures every 3 years, which provides a working framework for measurement, rather than a long-term mandate.

Prior to the Work Group meeting, leadership put forth a set of candidate measures for Work Group review and discussion. Candidate measures that adapted disease-specific measures to children were deferred to future revisions of disease-specific measurement sets in order to avoid duplication. The Work Group met on June 10, 2016, reviewed 12 candidate measures, and selected and modified 11 of the candidate measures for further consideration. These measures were further refined based on public comments. The Work Group approved the final 11 measures for inclusion in the AAN/CNS 2017 Child Neurology Quality Measurement Set (table).

Results

Child Neurology Quality Measurement Set

Ultimately, the Work Group identified 11 quality metrics for implementation in the care of children with neurologic disorders.

Although rare, infantile (epileptic) spasms are a source of significant morbidity, mortality, and resource expenditure in early life. There is controversy over what antiseizure medication to use first-line, but there is good evidence that ACTH, prednisolone, or vigabatrin are all reasonable choices.[39–42] Literature suggests that prompt treatment can potentially lessen the morbidity associated with IS and supports urgency in initiating appropriate therapy. While the precise critical period of the intervention is unknown, analysis of time to treatment in one large randomized trial showed that treatment initiation beyond 7 days after diagnosis was associated with worse developmental outcome at 4 years. This suggests that initiation of therapy by 7 days may be key to improved developmental outcomes.[6,43,44]

It has been more than a decade since the definition of SE was narrowed from a clinical seizure lasting longer than 30 to 5 minutes.[45] Human and animal literature indicates that the sooner prolonged seizures are treated, the greater the likelihood of termination. Thus, rescue therapy for children with convulsive seizures with an appropriate medication at a dose that is recommended to be effective should be provided for the prehospital setting. The intent is to reduce the morbidity and mortality that can accompany prolonged convulsive seizures.

Refractory SE is currently defined as seizures not responsive to first- and second-line antiseizure drugs that include one nonbenzodiazepine, and typically involves seizures lasting longer than 30 minutes. Although there is a paucity of formally conducted trials that assess timing of administration and head-to-head trials of different agents, consensus suggests that third-line medications with potential to treat refractory SE should be administered within 60 minutes of onset in the hospital or arrival in the emergency department.[16]

Children with epilepsy can have a variety of associated neurodevelopmental (e.g., specific learning) and neurobehavioral (e.g., attention-deficit/hyperactivity disorder, autism spectrum disorder) disabilities. These can adversely affect quality of life as much as or more than the actual epilepsy syndrome. It has been suggested that rather than comorbidities, these neurodevelopmental and behavioral difficulties are an integral part of epilepsy. Routine use of validated screening tools for neurodevelopmental and neurobehavioral abnormalities can allow for earlier diagnosis and improved outcomes. Use of these instruments should not add substantially to the resources required for the care of these children with epilepsy.

The most common movement disorder seen by child neurologists is TD, which is seen transiently in childhood, and includes TS. Although many tics of childhood are self-limiting, common comorbidities include attention-deficit/hyperactivity disorder, oppositional defiant disorder, obsessive-compulsive disorder, and mood disorders like anxiety and depression. As is the case for the epilepsies, these comorbid conditions can be extremely debilitating for the child and family. Evaluating for these conditions is possible by asking relatively simple questions in the outpatient setting, with subsequent referral for more precise diagnosis and treatment as needed. The management of tic-related

comorbidities can be performed by the child neurologist with appropriate pharmacotherapy or by referral to another care provider like a child psychologist or psychiatrist. Frequently, medications can often be avoided as behavioral therapy for chronic TD and TS can be as effective as pharmacotherapy in reducing the frequency of tics and improving quality of life. Several behavioral therapy approaches can be performed in an office setting by a child neurologist or by referral to a provider who specializes in these treatment paradigms. The type of therapy chosen should be tailored to the needs of the child as well as her or his ability to cooperate based upon level of intellectual development and behavioral competence.

Despite a variety of pharmacologic options, migraine can become a chronic and debilitating condition in childhood. Psychological interventions (cognitive-behavioral therapy, biofeedback, or relaxation therapy) have been demonstrated to provide significant symptom relief and improve quality of life.

Spasticity and dystonia, when localized or segmental, can have morbidity including pain and limitation of movement, which can interfere with hygiene/care and with the implementation of other therapies such as orthoses. The care of children with spasticity and dystonia is best accomplished by a team of individuals to provide multifaceted treatment approaches tailored to the needs of the patient. These patients should be evaluated (or referred for evaluation) to a care provider experienced in the use of botulinum A toxin, which has been demonstrated to be effective in reducing spasticity and dystonia. In addition to symptom relief, early use of this treatment modality can allow for improved function during a critical period of motor development.

GDD is a common problem that is referred to the pediatric neurologist. The lack of a definitive diagnosis can delay onset of therapies for treatable conditions, therapy, affect discussion related to prognosis and genetic counseling, and frequently leads to unnecessary diagnostic testing. The latter can be invasive (e.g., lumbar puncture, muscle biopsy), expensive, and lead to additional testing that may not be relevant. In this context, it is reasonable to perform chromosomal microarray (CMA) as first-line testing. Although CMA has sensitivity and specificity limitations (like all other tests), it is the current gateway to genetic diagnoses of GDD.

Preparing patients and families for transition to adult care is one of the most important tasks to be performed in the longitudinal care of a child with a chronic neurologic disorder. A variety of factors can influence creation and understanding of this care plan including the developmental status of the child, as well as the need for and availability of ongoing neurologic care by an adult provider. Nevertheless, guidelines suggest that a written plan is in the best interest of the patient and the written plan should cover the medical, emotional, social, legal, and financial needs associated with transition to adult life.

Discussion

These quality measures represent a starting point for measure development in child neurology. They are designed to allow child neurologists to measure performance in areas where there are potential gaps in care. Further work will be needed to identify and address other existing gaps in care. The Work Group recognizes that resource gaps exist and may need to be addressed to ensure success in complying with these quality measures and ongoing advancement of best practices. The proposed quality measures are not intended to be used as proof of failure to provide optimal care when local resources may not be able to accommodate. The idea is not for these measures to be used as guidelines or for the purposes of punishment for low performance. Each child neurology provider should take these measures and evaluate their current baseline. Then, by setting a goal for improvement of care, quality improvement methodology can be implemented to improve the outcomes and lives of patients with pediatric neurologic illnesses.

Author contributions

Dr. Berg and Dr. Billinghurst contributed to acquisition of data, analysis or interpretation of data, and critical revision of the manuscript for important intellectual content. Dr. Buchhalter contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision. Dr. Fain, E. Fecske, Dr. Feyma, Dr. Grinspan, Dr. Houtrow, Dr. Kothare, and Dr. Kumar contributed to acquisition of data, analysis or interpretation of data, and critical revision of the manuscript for important intellectual content. E. Lee contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision. Dr. Monduy and Dr. Morita contributed to acquisition of data, analysis or interpretation of data, and critical revision of the manuscript for important intellectual content. Dr. Patel contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision. Dr. Szperka contributed to acquisition of data, analysis or interpretation of data, and critical revision of the manuscript for important intellectual content. Dr. Victorio contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision. Dr. Yeh contributed to acquisition of data, analysis or interpretation of data, and critical revision of the manuscript for important intellectual content.

Acknowledgment

The authors thank the Child Neurology Quality Measurement Set Work Group members for their dedication, time,

energy, contributions, and work that supported the development of this article. Jeffrey Buchhalter, MD, FAAN (Chair, Child Neurology Society); Anup Patel, MD, FAAN (Chair, American Academy of Neurology); Karen Ballaban-Gil, MD (American Academy of Neurology); Anne Berg, PhD (American Academy of Neurology); Daniel Fain, MD, FAAN (American Academy of Neurology); Cynthia Keator, MD (American Academy of Neurology); Sanjeev Kothare, MD (American Academy of Neurology); Gogi Kumar, MD (American Academy of Neurology); Migvis Monduy, MD (American Academy of Neurology); Diego Morita, MD (American Academy of Neurology); Zachary Grinspan, MD, MS (American Academy of Pediatrics, Child Neurology Society); Erin Fecske, MSN, RN, CNRN, CPNP (American Association of Neuroscience Nurses); Amy Houtrow, MD, PhD, MPH (American Academy of Physical Medicine and Rehabilitation); Kevin Chapman, MD (American Epilepsy Society); Christina Szperka, MD (American Headache Society); Lynn Jeffries, PT, DPT, PhD, PCS (American Physical Therapy Association); Tim Feyma, MD (Child Neurology Society); Kiran Maski, MD (Child Neurology Society); Lisa Meunier (Epilepsy Foundation); Lori Billinghurst, MD, MSc, FRCPC (independent); Ann Yeh, MD (independent); David Michelson, MD (Facilitator, American Academy of Neurology); M. Cristina Victorio, MD (Facilitator, American Academy of Neurology); Amy Bennett, JD (American Academy of Neurology staff); Gina Gjorvad (American Academy of Neurology staff); Erin Lee (American Academy of Neurology staff); Becky Schierman, MPH (American Academy of Neurology staff).

Study funding

No targeted funding reported.

Disclosure

A. Patel receives research grants from the Pediatric Epilepsy Research Foundation, Upsher-Smith, GW Pharmaceuticals, and LivaNova. He consults for GW Pharmaceuticals and LivaNova. He is on a scientific advisory board for UCB Pharma and Supernus. A. Berg and L. Billinghurst report no disclosures relevant to the manuscript. D. Fain is a subinvestigator for the following study as of September 6, 2016: A Randomized, Double-Blind, Placebo-Controlled Study to Evaluate the Efficacy and Safety of Sage-547 Injection in the Treatment of Subjects with Super-Refractory Status Epilepticus, Protocol number 547-SSE-301. E. Fecske and T. Feyma report no disclosures relevant to the manuscript. Z. Grinspan receives funding from the Centers for Disease Control and Prevention, the Pediatric Epilepsy Research Foundation, and the Nanette Laitman Clinical Scholars Program. A. Houtrow, S. Kothare, and G. Kumar report no disclosures relevant to the manuscript. E. Lee is an employee of the American Academy of Neurology. M. Monduy and D. Morita report no disclosures relevant to the manuscript. C. Szperka received funding from Pfizer and Miles for Migraine. M. Victorio reports no disclosures relevant to the manuscript. A. Yeh receives research funding from the NMSS, CMSC, IORM, SCN, CBMH, Chase an Idea, SickKids Foundation, Rare Diseases Foundation, MS Scientific Foundation (Canada)/MS Society, McLaughlin Centre, and Mario Battaglia Foundation. She has received unrestricted funds to run an educational symposium from the Guthy Jackson Charitable Foundation and Teva. She has served on a scientific advisory board for neurotoxicity for Juno. She serves as a relapse adjudicator for ACI. She has received honorarium for a talk from Novartis. J. Buchhalter is on the Scientific Advisory Board of the Charlie Foundation. He receives research funding from the Alberta Children's Hospital Research Institute and the Department of Pediatrics, University of Calgary, Alberta, Canada. Go to Neurology.org/N for full disclosures.

Received May 17, 2017. Accepted in final form September 25, 2017.

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