CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

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Providing a Primary Care Medical Home for Children and Youth With Cerebral Palsy

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Cerebral palsy (CP) is the most common motor disorder of childhood, with prevalence estimates ranging from 1.5 to 4 in 1000 live births. This clinical report seeks to provide primary care physicians with guidance to detect children with CP; collaborate with specialists in treating the patient; manage associated medical, developmental, and behavioral problems; and provide general medical care to their patients with CP.

Cerebral palsy (CP) is the most common motor disorder of childhood, with prevalence estimates ranging from 1.5 to 4 per 1000 live births.[1,2] In resource-abundant countries, the incidence among newborn infants may be decreasing because of advances in perinatal care.[3]

All physicians who provide care for children must be familiar with the definition, manifestations, and management of CP. This clinical report updates previous guidance[4] and specifically seeks to provide pediatricians, other physicians caring for children, and nonphysician clinicians with guidance to detect CP in children; collaborate with specialists treating patients with CP; manage the medical, developmental, and behavioral problems associated with CP; and provide general medical care to their patients with CP.

Definitions

As our understanding of CP has changed in recent years, it is helpful to start with a common definition of the condition. The most current consensus definition of 2006 states that "cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by

abstract

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disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems."[5]

The term CP describes a group of disorders or what may be considered a phenotype. It is considered a phenotype because there are different brain disturbances that can result in a common clinical picture of motor disability. These include intrauterine and perinatal infections, intraventricular hemorrhage, hypoxic-ischemic encephalopathy, stroke, cerebral malformations, genetic disorders, and several others. In the past, CP was assumed to be attributable to an injury to the brain in the birth process, but it is now known that <10% of cases are related to perinatal asphyxia.[6] Most children with low Apgar scores do not develop CP, and most children with CP had high Apgar scores.[7] As many as 30% of patients likely have a genetic etiology for their CP.[8]

These etiologies are permanent and nonprogressive, in that the brain disturbance is not ongoing or worsening; however, the physical manifestations of movement and posture problems can change over time. CP is not considered static in that sense. For example, changes in gait, pain, or posture may be related to the underlying CP as a result of worsening contractures, poorly controlled tone, or progressive subluxation or dislocation of a hip, etc. However, symptoms ought not to be assumed to be related to CP without proper investigation into other causes.

Clinicians and researchers have attempted to use a common language to describe various attributes of patients with CP; many of these terms will be used throughout this report. In terms of motor abilities, children with CP exhibit a wide range of characteristics, from mild deficits in higher-order functions (running, jumping, etc) to significant disability, in which children are transported by others in a wheelchair and are often dependent on others for their care and activities of daily living. A common system for describing gross motor abilities in CP is the Gross Motor Functional Classification System (GMFCS);[9] see Fig 1. The GMFCS is easy for patients and families to comprehend and is fairly stable over time, especially after the age of 2 years;[10,11] future gross motor function can be predicted from current functioning with some, but not perfect, certainty. Families have indicated a desire to understand their child's motor function using the GMFCS as well as a desire to revisit it over time.[12] The Manual Ability Classification System is a systematic way to describe how individuals with CP use their hands together to manage daily activities such as eating, dressing, and playing.[13] The Communication Functional Classification System (CFCS) describes communication abilities.[14]

"Topography" refers to the parts of the body affected by CP. The brain may be affected unilaterally or bilaterally, leading either to unilateral or bilateral symptoms. Purely unilateral brain abnormalities are not very common, although patients may have bilateral abnormalities with clinical findings notably more pronounced on one side than the other. "Hemiplegic CP" indicates predominantly unilateral involvement. Bilateral symptoms may be described as "quadriplegia" if all 4 limbs are affected, "diplegia" if the legs are predominantly affected, or "triplegia" if there is relative sparing of 1 arm. Topography alone does not predict function; some children with quadriplegia may be able to ambulate and some with diplegia may not. Motor function is graded using the GMFCS as described above.

It is important to describe the type of motor or movement disorder that is present, because it can give clues as to the location of the brain disorder and inform the types of treatment that could be offered. Abnormality in tone, particularly spasticity, is most common. Spasticity is "velocity-dependent" hypertonia that increases with greater speed of passive joint range of motion. Spasticity is usually associated with damage to white matter tracts. Dystonia is both a tone disorder and a movement disorder in which involuntary sustained or intermittent muscle contractions cause twisting and repetitive movements, abnormal postures, or both. Dystonia often coexists with spasticity and can be associated with abnormalities in the basal ganglia (Table 1).[15] Less common movement patterns include ataxia (abnormal, uncoordinated movements), athetosis (continuous, involuntary writhing movements), chorea (brief, irregular contractions that are not repetitive or rhythmic but appear to flow from 1 muscle to the next), or some combination of these. When these are present, referral to a specialist can be helpful for diagnosis and management. An individual patient's tone may evolve over time. For instance, many children with CP are hypotonic in infancy and early childhood, especially in the trunk, with spasticity and dystonia emerging later. Management of spasticity and dystonia is discussed later in the paper.

An Integrated Approach

Although CP is a motor disorder caused by a disturbance in the brain, difficulties in other areas of the nervous system and nonneurologic comorbidities may exist. Common problems include epilepsy, cognitive and communication issues, respiratory symptoms, gastrointestinal and urinary problems, and pain. These will be discussed in detail in this clinical report. In addition to providing general medical care, 1 responsibility of the primary care

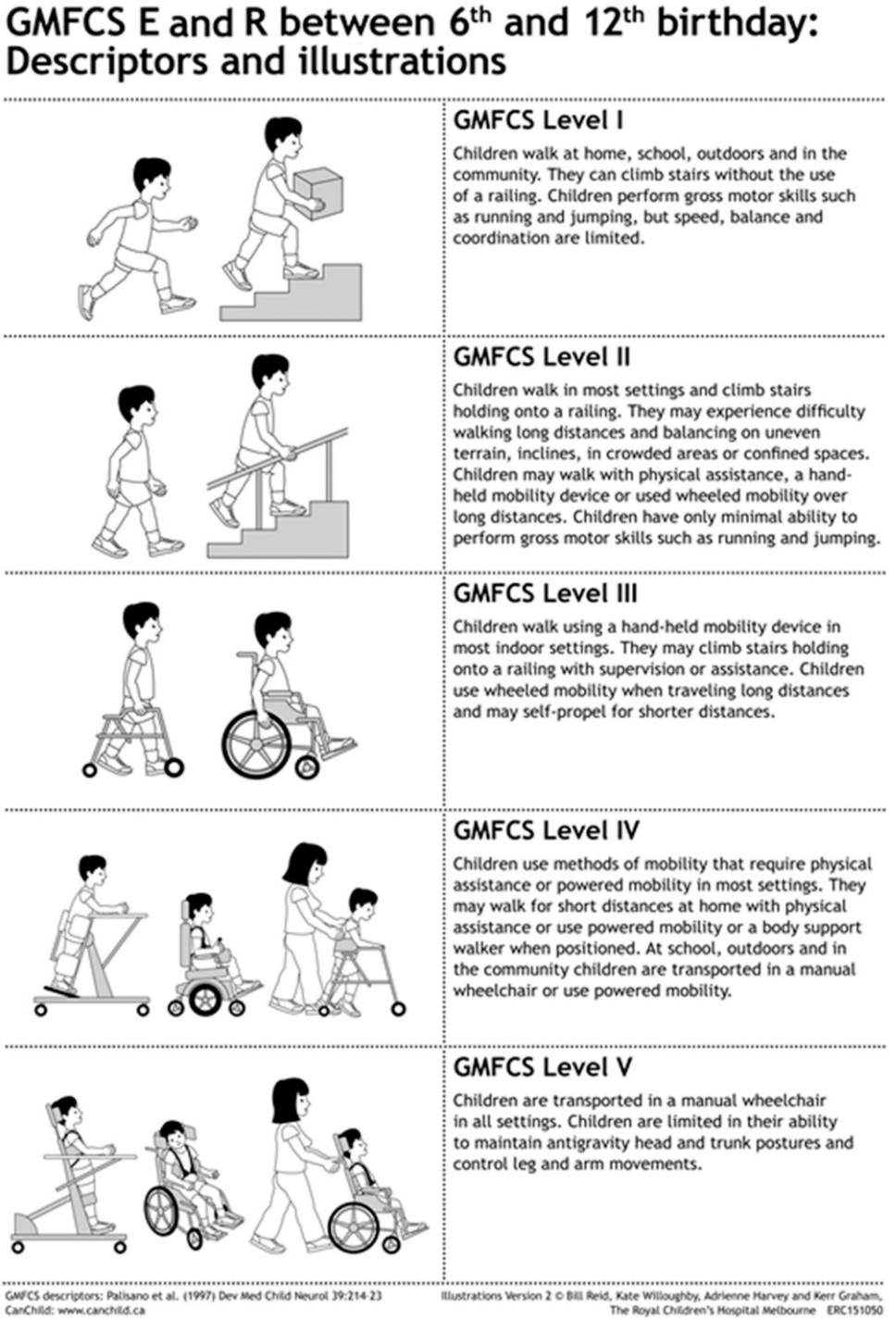

FIGURE 1

GMFCS E and R between sixth and 12th birthday: descriptors and illustrators. Reproduced with permission from the following author and illustrator: Author: GMFCS descriptors: Palisano et al, (1997) *Dev Med Child Neurol* 39:214–23 CanChild: www.canchild.ca. Illustrator: Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham, The Royal Children's Hospital Melbourne ERC151050.

physician (PCP) is to integrate and orchestrate care across multiple organ systems and multiple specialists (the "medical neighborhood") while providing families with resources and support to help the child or adolescent thrive. This can be accomplished through collaboration with community partners, including early intervention programs, school systems, insurance companies, and others.

TABLE 1 Comparison Chart of Principal Differentiating Diagnostic Features

	Spasticity	Dystonia	Rigidity
Summary	Velocity-dependent resistance	Sustained or intermittent muscle contractions	Independent of both speed and posture
Effect of increasing speed of passive movement on resistance	Increases	No effect	No effect
Effect of rapid reversal of direction on resistance	Delayed	Immediate	Immediate
Presence of a fixed posture	Only in severe cases	Yes	No
Effect of voluntary activity on pattern of activated muscles	Minimal	Yes	Minimal
Effect of behavioral task and emotional state on pattern of activated muscles	Minimal	Yes	Minimal

Reproduced with permission from: Sanger TD, Delgado MR, Gaebler-Spira D, Hallett M, Mink JW. Classification and definition of disorders causing hypertonia in childhood. *Pediatrics.* 2003;111(1):e89–e97.

Many medical centers have a multidisciplinary team available to evaluate and treat children with CP. These can be difficult to access for families in rural areas or those with transportation difficulties. Those with such barriers may depend more heavily on their local resources, medical home, and pediatrician for urgent or acute care challenges. For patients receiving care across multiple physicians or health systems, it can be important to delineate responsibilities across the care teams and to facilitate needed care (such as hip surveillance) while minimizing duplication. This collaboration can be accomplished through the use of a patient- or family-centered care plan. This arrangement is likely to be different for different patients and dependent on local resources.

Disparities

Preterm birth plays a significant contributory role in the risk of CP, as nearly half of people with CP were born prematurely.[3] Social factors, as well as the possibility of underlying genetic variations and gene-environment interactions, have all been posited as determinative variables in the etiology of preterm birth.[16,17] Although the complexity of the precise antecedents and perinatal contributors to the causal pathway for preterm birth are incompletely understood, population-level studies of CP prevalence demonstrate a racial disparity.[18] CP is more commonly diagnosed among children identified as non-Hispanic Black than non-Hispanic white or Hispanic. Because race assignment is a social rather than a biological construct, race and racism as social determinants of health cannot be discounted among the factors to which these disparities may be attributable. Systemic societal inequities, as well as those within the medical system, can confer deleterious lived experiences for women from historically minoritized groups before and during pregnancy. Differential exposures to risk and protective factors likely contribute to the observed disparities in having a child with CP.[19] Efforts to combat racism and eliminate barriers to culturally sensitive prenatal, perinatal, and later pediatric care may help to improve outcomes for all children with CP.

Aside from race, CP is also known to be more prevalent in children who come from families with lower socioeconomic status. The knowledge of these disparities may prompt physicians to identify implicit biases and barriers to screening, identification, treatment, and familial support for children with CP whose lives are impacted by social determinants of health.[20] Further research is needed to better understand and address these disparities, and changes in social and economic policies at the societal level are needed to reduce them.[3]

Barriers to Care

The care of children with CP can be extremely complex and costly, both for the family[21] and medical providers. Children and families may be eligible for a range of services that are, in reality, difficult to access.[22] These services include home nursing services and durable medical equipment, such as wheelchairs, transportation, respite care, and others. Families may have trouble navigating the complicated systems tasked to provide these services, especially if they have language barriers or low health literacy. Where available, social workers and care coordinators can be helpful, but families are often left to manage care on their own. Medicolegal partnerships may be available to assist families in maintaining their legal rights to health care, education, and public benefits.

Payment for physician services is often inadequate in comparison with the amount of work performed by the medical home to provide expert, coordinated care for children. The breadth of the pediatrician's care, as illustrated in this clinical report, is difficult to sustain solely through payment for intermittent office visits.[23] Because visits with patients

with CP are likely to take longer than typical visits, time-based billing codes can be used to more accurately report the amount of effort needed to provide care in the office. Although care coordination codes exist for billing purposes, these are often onerous to report and poorly reimbursed, if at all.[24] Alternative payment models, as might be available through an accountable care organization, could be expanded to assist medical homes in the care of children with CP.[25,26] Medical and surgical specialists with expertise in treating children with CP are often difficult to access, either because of scarcity, distance, or insurance arrangements.[27] American Academy of Pediatrics (AAP) policy states, "Managed care plans should contract with the appropriate number and mix of geographically accessible pediatric-trained physician specialists and tertiary care centers for children."[28]

Pediatricians can advocate for their patients on an individual level and with Medicaid and other payers at the state and federal levels to champion for adequate resources to achieve best outcomes for children with CP. The American Academy of Pediatrics (AAP) policy states, "Payers, public and private, should invest in the necessary infrastructure to support the pediatric medical home and medical neighborhood. Where they exist, payers should support community-based efforts that identify children and adults in high-risk families, provide care coordination, and measure results in housing, education, employment, and engagement with the health system."[29]

SCREENING, SURVEILLANCE, AND DIAGNOSIS OF CEREBRAL PALSY AND OTHER MOTOR DISORDERS

Since the first version of this AAP clinical report was published, there is increasing recognition of the importance of detecting CP and other neuromotor disorders as early as possible. Early diagnosis is challenging, because CP can occur in children with or without known risk factors, such as prematurity or kernicterus. For CP, early identification and initiation of evidence-based motor therapies can improve outcomes by taking advantage of the neuroplasticity in the infant brain.[30,31] Although CP is the most common motor disorder, screening may also identify less common but treatable disorders. In neuromotor disorders, such as spinal muscular atrophy or lysosomal storage diseases, greater functional outcomes are observed when treatments are started early.[32,33] Even if no specific therapy is available, families report that early identification is desired and helpful as it allows for early connection to family resources and shortens the "diagnostic odyssey."[34]

Some children will be identified as having risk factors for CP and other developmental problems because of factors from the medical history, such as preterm birth and other pre or perinatal problems (Table 2). For these patients, PCPs can work with neonatal follow-up programs, developmental and behavioral pediatricians, neurodevelopmental pediatricians, and therapists to further evaluate these children using validated tools, such as the General Movements Assessment or the Hammersmith Infant Neurologic Examination.[31] These examinations are highly sensitive and specific when performed by specially trained clinicians. If such clinicians are available, they can evaluate any child for whom there is a motor concern up to 5 months' corrected age (for General Movements Assessment) or 24 months (for Hammersmith Infant Neurologic Examination).

One of the core tasks for the PCP in the medical home is to provide health promotion services according to *Bright Futures* recommendations, including surveillance and screening for developmental differences in young children. Surveillance is the ongoing process by which pediatricians elicit and monitor developmental progress at all health maintenance visits. Promotion of parental understanding of typical development is integral to this process, and tools such as "Learn the Signs. Act Early" can be suggested.[35] Screening refers to the use of standardized tools to detect developmental issues at specified intervals in early childhood or anytime the family or provider has a concern about a developmental problem. The AAP recommends that these standardized screens be administered at 9, 18, and 30 months of age to evaluate for delays in the attainment of developmental milestones.[36] Screening for motor disorders in particular is recommended at these ages, including a neuromotor examination with particular attention to acquisition of motor milestones and assessment of muscle tone.[37]
A discussion on screening and specialized tools used for early diagnosis of CP can be found in the Early Detection of CP Care Pathway from the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM). This evidence-based guideline is periodically updated and available at https://www.aacpdm.org/publications/care-pathways/early-detection-of-cerebral-palsy.

Table 3 illustrates elements of the history or examination that may alert the PCP to the possibility of CP. The presence of these elements does not mean that CP is definitely present, and their absence does not mean that CP can be excluded.

When a child is identified as having a possible neuromotor disorder, the AAP recommends that the PCP take 3 actions simultaneously: (1) initiate the diagnostic workup based on the suspected disorder; (2) refer to a

TABLE 2 Mechanisms Leading to Cerebral Palsy

Timing	Type of Mechanism	Examples
Prenatal	Intrauterine pathologic processes	Placental vascular disease
		Intrauterine growth retardation
		Infection with fetal inflammatory response
		Congenital or genetic anomalies
Peri-natal	Peri-partum events	Birth asphyxia
		Chorioamnionitis
		Placental abruption
Postnatal	Neonatal complications	Intraventricular hemorrhage
		Sepsis or meningitis
		Periventricular leukomalacia
	Late complications	Hypoxic-ischemic brain injury
		Nonaccidental trauma
		Meningitis or encephalitis

Adapted from Figure 1, (Stavsky, Mor et al 2017). Reproduced with permission from "Children and Youth with Complex Cerebral Palsy: Care and Management" edited by Laurie Glader and Richard Stevenson. Published by Mac Keith Press (www.mackeith.co.uk), 2019, 978-1-909-96298-9.

medical specialist, such as a pediatric neurologist, pediatric physiatrist, geneticist, or developmental pediatrician, to complete the diagnostic evaluation; and (3) refer for treatment to early intervention programs and therapists.[37] For PCPs who do diagnose CP, it still remains important to engage the collaboration of medical and surgical specialists experienced with musculoskeletal and neurologic problems as they arise. A diagnostic specialist may also investigate any concern that the underlying diagnosis may be a CP "mimic," such as a metabolic or genetic syndrome.[38]

Neuromotor delay with an increase in muscle tone suggests a disorder of the central nervous system, so the PCP may order imaging of the brain, preferably by MRI.[39] The presence of generalized low muscle tone suggests a disorder outside the central nervous system, so it is recommended to check creatine kinase and thyroid-stimulating hormone levels in the blood. If weakness with tongue fasciculations or areflexia are observed, a motor neuron disorder such as spinal muscular atrophy may be present and specific genetic testing for that disorder is needed. Weakness or paralysis of 1 arm in an infant may lead to the suspicion for a brachial plexus injury.[40] These investigations can be completed while arrangements are made for consultation with specialists and treatment by therapists.

There is increasing recognition of the role that genetic variants have in the etiology of CP,[8] and the child's diagnostic evaluation may include advanced genetic techniques, such as chromosomal microarray and genomic sequencing. Genetic testing can yield causative or predisposing diagnoses even in patients with known risk factors for CP, such as prematurity or birth asphyxia.[41] For PCPs who order genetic evaluations, counseling the families is important. Collaboration with a clinical geneticist or genetic counselor can help with these processes if needed.[42]

Once the diagnosis of CP is established, the PCP can turn attention to maximizing the child's potential and caring for the medical and psychosocial needs of the child and family. Hearing and vision evaluations are recommended at the time of diagnosis to optimize sensory input.[31] Referrals are recommended to early intervention programs, special education services, and state resources for children with special health care needs (Title V, community health workers, etc). Some children with CP may be eligible for income support through Supplemental Security Income, secondary insurance through Medicaid, and home- and community-based services through Medicaid. Medical homes can conduct screening for social determinants of health to identify families in need of additional services.

TABLE 3 Elements of the History or Examination That May be Seen in Children With CP

Perinatal History	Developmental History	Examination Findings
• Prematurity	• Early rolling	• Increased or decreased muscle tone
• Low birth weight	• Thumb in fist after 7 m	• Scissoring of the legs
• Neonatal encephalopathy	• Inability to sit by 9 m	• Asymmetric strength or reflexes
• Neonatal seizures	• Milestones attained "out of order" (able to pull to stand before able to sit)	• Opisthotonus
• Neonatal stroke or other known brain abnormality	• asymmetric creeping or crawling	• Persistent primitive reflexes
• Congenital infection	• Inability to walk by 18 m	• Combination of ankle clonus, brisk deep tendon reflexes and persistent Babinski after 18 m
• Chorioamnionitis	• Persistent toe walking	
• Neonatal meningitis		
• Known hypoxic event		

The presence of these elements does not mean that CP is definitely present, and their absence does not mean that CP can be excluded.

Early linkage to parental resources, such as parent mentors and online communities, may be helpful. PCPs may want to familiarize themselves with national and local sources of support and share such with families. State specific information on services for children with special health care needs can be found online at https://mchb.hrsa.gov/maternal-child-health-initiatives/title-v-maternal-and-child-health-services-block-grant-program. Families may be advised that although these can be an important source of support, advice regarding medical treatments can be carefully vetted in partnership with the PCP or specialist. Families searching the internet for information on CP may encounter (or be targeted by) websites or testimonials recommending legal action as a result of labor and delivery experiences or advertising treatments that are known to be ineffective and harmful. A partial list of trusted resources is in Table 4.

PROGNOSIS FOR CEREBRAL PALSY

Once a diagnosis of cerebral palsy is given to a child, it is likely that the family will have questions regarding the child's "prognosis." The first step in answering this question honestly and compassionately is to find out the true nature of their question. Are they asking if the child will walk independently? Live a normal life expectancy? Be independent? Have a good life? Some of these questions can be answered with a modicum of confidence, but others require a great deal of prognostic humility.

In terms of independent walking, some data guide the prognostic conversation. Children who can sit independently and pull to stand by the age of 24 months have a high likelihood (76%) of eventual independent ambulation.[43] When children are classified using the GMFCS after 24 months, their eventual gross motor function can be predicted fairly reliably, although not certainly.[11] For example, a 2-year-old child whose preferred method of mobility is crawling with a reciprocal pattern or cruising while holding on to furniture is classified at GMFCS Level II. By the age of 12 years, a child who remains at Level II is most likely to walk independently in most settings but might benefit from a hand-held mobility device (such as a cane) in crowded settings and might prefer to use wheeled mobility for long distances. Before the age of 2 years, the GMFCS classification is less reliable, with only 60% of patients remaining at the same GMFCS level later.[44] Similarly, approximately one third of young adults with CP report a decline in their gross motor function.[45] Descriptions of these motor predictions are available in several languages at https://canchild.ca/en/resources/42-gmfcs-e-r.

TABLE 4 Resources for Families: Overall Family Support

Resources for Families	
The Cerebral Palsy Foundation	https://www.yourcpf.org/
The CP Research Network	https://cprn.org/
United Cerebral Palsy	http://www.ucp.org/
CP Toolkit for Families	https://cpnowfoundation.org/wp/wp-content/uploads/2015/11/CP-ToolKit.pdf
Understanding CP	http://www.mychildwithoutlimits.org/ (English and Spanish)
Healthy Bodies (puberty resources for children with disabilities)	https://vkc.vumc.org/healthybodies/ (English, Spanish, and Turkish)
F-words tools	https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability/f-words-tools
CP Channel (videos for parents about CP)	Available at APP store (free, iPhone only)
Family Voices and Family-to-Family Health Information Centers	www.familyvoices.org

If the prognostic question concerns life expectancy, some data exist for guidance.[46] The most important factors associated with life expectancy appear to be degree of independent mobility and whether the child can feed himself or herself. Caution is needed in explaining the meaning of life expectancy to the family. It is not how long we expect this particular child to live. Rather, it is a description of the group of children similar to this particular child. For example, the reported median life expectancy for a 15-year-old boy who cannot lift his head and receives tube feeds is 14 additional years, which means that half of similar children are expected to survive to age 29 and beyond, and half are not. This illustrates that there are a variety of disease trajectories, even in the most significantly affected children with CP, and advanced care planning is beneficial when the child appears to have a life-limiting prognosis. Engagement with a palliative medicine specialist may be advantageous. See the section on "Palliative Care" below.

The major determinants of independence in adulthood are the degrees of motor, cognitive, and communication ability; the preparations that have been made to support independence; and the adaptations that are available to support the person in the environment.[47] There can be frequent conversations as children with CP mature as to their goals and expectations for independence. Many manifestations of independence are possible, from completely independent living to group homes with supports, and there is considerable variation between communities as to what is available. The extended team of family, medical, educational, and social professionals can improve prognosis by facilitating independence for the individual

through supported decision making and transition planning. See the section "Transition and Transfer of Care" below and resources available at https://www.gottransition.org/.

Discussion of prognosis warrants mention of what has been termed the "disability paradox," a phenomenon in which many individuals with disabilities report that they have a good quality of life despite their limitations and contrary to what others, including health care workers, perceive.[48] Most children and adolescents with CP who are able to self-report indicate a similar quality of life as those in the general population in many domains.[49–53] In a study of adolescents with CP, the only domain in which they reported significantly lower quality of life than controls was social support and peers, and adolescents with CP reported higher quality of life than controls in some domains.[53] In multiple studies, youth with CP self-report a better quality of life compared with their parents' report about the youth's quality of life.[49,50,51] The degree of impairment explains only a small part of the variance in quality of life among children and adolescents with CP.[52,53] However, pain is consistently associated with reduced quality of life.[52,53] This is important for pediatricians to be aware of because addressing pain could improve quality of life for these patients. See section on "Pain" below. Supporting friendship and participation in social activities can also be beneficial.

ANTICIPATORY GUIDANCE, HEALTH PROMOTION, AND DISEASE PREVENTION

Children with CP need the same approach to primary care as all other children, as specified in *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents,* fourth Edition.[54] However, there are several areas related to health promotion and disease prevention that require special attention.

Immunizations

In addition to the recommended vaccination schedule (available at cdc.gov), people with severe CP and chronic lung disease are at risk for pulmonary complications and, thus, are eligible to receive additional doses of pneumococcal vaccines.

Vehicle Safety

Proper restraint in motor vehicles of patients with CP can be difficult and may require specialized equipment but is critical to preventing unintentional injury. Patients may not fit safely in typical car safety seats because of musculoskeletal deformities or may be unable to maintain a safe, upright posture because of weakness or tone abnormalities. The AAP provides specific guidance regarding vehicle safety for children with CP. Specialized adaptive car seats or wheelchair restraint systems may be needed for some.[55] The PCP can assist by referring to occupational or physical therapists for seating suggestions and writing prescriptions for this medically necessary equipment.

Evaluation for Sensory Impairment

Performing routine hearing and vision screening throughout childhood is particularly important, because individuals with CP demonstrate a greater likelihood of sensory impairments attributable to the underlying brain injuries that result in CP. Hearing and vision screening can occur at the ages recommended by the AAP for all children starting in infancy.[56,57] Some children will require specialty evaluations by ophthalmology and/or audiology if they are unable to participate in office screenings or because of specific risk factors (eg, retinopathy of prematurity, congenital cytomegalovirus).[56,58–60]

Dental Care

Dental care for people with CP can be difficult to provide. Families may struggle to maintain dental hygiene because of oral aversions or dysphagia. Children who receive nutrition by feeding tube are at increased risk for caries and dental calculi.[61] Certain antiseizure medications, such as phenytoin, may increase the risk of periodontal disease.[62] In addition, dental care may be challenging to access because of difficulty sitting in the dental chair, behavioral issues, or insurance coverage. Pediatricians are key to helping parents access these resources, and patients with CP are more likely to receive regular dental care if they have a medical home.[63] Because some patients with CP may receive bisphosphonates for the treatment of osteoporosis (see section below), diligent dental hygiene is important to prevent osteonecrosis of the jaw, a known but very rare complication of that class of medication.[64]

Prevention of Cardiovascular Disease

Adults with CP have increased rates of early cardiovascular disease and metabolic syndrome,[65] so it is important that pediatricians help their patients establish heart-healthy habits early. As a group, children, youth, and adults with CP lead more sedentary lives than their unaffected counterparts,[66] so the pediatrician can help the family find appropriate resources in the community to support good exercise habits from early childhood.[67] The critical role of nutrition in patients with CP is explored in depth later in the clinical report. The AAP currently recommends that routine screening for hyperlipidemia begin at age 9 to 11 years or earlier if there are risk factors.[68]

Prevention of Maltreatment and Neglect

Children with disabilities and special health care needs account for a disproportionate percentage of cases of child maltreatment, with increased risk of physical, sexual, and emotional abuse and neglect.[69–71] The caregiving demands associated with having a child with a disability can lead to caregivers feeling overwhelmed, leading to increased possibility of abuse and neglect.[69] Complex medical needs, such as the need for frequent medication administration or numerous medical appointments, can contribute to the risk of medical neglect. The presence of comorbid intellectual developmental disorders (otherwise known as intellectual disability) increases the likelihood of abuse, as do behavioral disorders.[69–71] Demographic and psychosocial factors also contribute to the increased risk of maltreatment in some children with CP.[70,71] Identifying maltreatment in this population may be difficult, because some children are not able to verbalize what has happened.[69] In addition, limitations in balance and coordination place these children at higher risk for accidental injuries, such as falls with ambulation. Children with CP who are nonambulatory may have low bone density and develop fractures with minimal trauma, whether inflicted intentionally or accidentally. Pediatricians can help reduce the occurrence of maltreatment by educating caregivers regarding prevention and indicators of abuse and by identifying family stressors and making referrals for support services. Further guidance for pediatricians is available in the AAP clinical report "Maltreatment of Children With Disabilities."[69]

Adolescent Considerations

Preparation for puberty, menstruation, and healthy, safe sexual relationships needs to be part of primary health care for all youth, including those with CP. Adolescent care for youth with CP includes screening and performing assessments for sexual activity, substance use, mental health problems, and doing appropriate testing (if indicated) as is standard for all youth.[54] The approach for each patient needs to be individualized and geared toward the patient's capacity. See the puberty and sexual health section for further details.

INTERVENTION PLANNING

Care for patients with developmental disabilities has traditionally been approached using the medical model, which focuses on diagnosing a specific problem and treating with a specific intervention. However, chronic neurodevelopmental conditions such as CP tend to be less precise diagnoses, have multiple influences, and often do not have a specific intervention that leads to a cure. The International Classification of Functioning, Disability, and Health (ICF) is an alternative to the traditional medical model approach to healthcare and disability[72] (Fig 2). This is a biopsychosocial model based on integration of the social and medical models. The ICF provides a framework for describing and organizing information on functioning and disability, recognizing the dynamic interplay between health conditions, environmental influences, and personal and family factors. Use of the ICF framework to approach the clinical care of individuals with disabilities helps to shift the focus from specific impairments to the whole person and from cure to promotion of function, participation in activities, and quality of life. Application of the ICF to childhood disabilities has been conceptualized as 6 "F words": function, family, fitness, fun, friends, and future.[73] Considering these aspects of a child's life helps to focus on child and family strengths and optimizing development and health. A strengths-based approach to intervention planning highlights what individuals can do and their potential rather than deficits.[74] This approach can guide considerations of intervention options and shape discussions with patients and families. Providing a positive framework to discussions of developmental assessment results and therapy goals supports collaborative relationships among patients, family, and professionals and promotes family-centered care.[74] Information and tools to help pediatricians incorporate ICF concepts in their practices are available at http://learn.phsa.ca/shhc/icf/story_html5.html and https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability.

Among the many roles of a pediatrician when taking care of a patient with CP is the need to write prescriptions for therapies, including occupational, physical, and speech therapies.[4,75] Although pediatricians often do not receive specific training in this skill, guidance for primary care pediatricians in how to approach and write these prescriptions has been published by the AAP.[75] Input from other specialists involved in the child's care, such as pediatric physiatry, neurology, developmental pediatrics, and orthopedics, may be valuable in formulating the details of these prescriptions, especially if the child has had a recent surgery or needs specialized adaptive equipment. The assessment and recommendations of the therapists themselves can be integrated into the therapy plan.

Therapies can be delivered in the outpatient, community, home, or school setting. These services may be covered by a child's insurance or provided through early intervention or the public school system under the Individuals with Disabilities Education Act (IDEA). Therapies

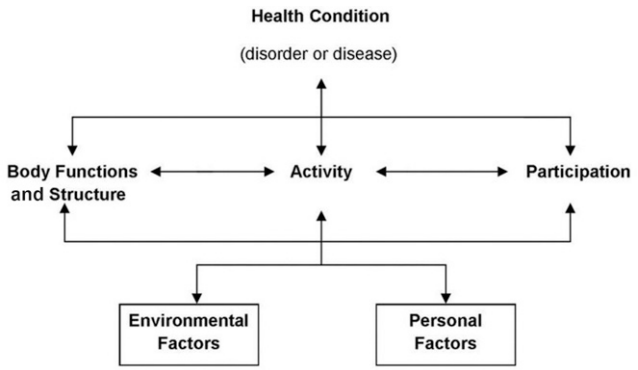

FIGURE 2

The World Health Organization International Classification of Functioning, Disability and Health. Reproduced from World Health Organization. Towards a common language for functioning, disability and health. In: *International Classification of Functioning, Disability and Health.* Geneva, Switzerland: Copyright World Health Organization; 2002:9.

can teach skills, improve physical function, prevent future physical limitations, and enhance participation in developmentally appropriate activities.[75] Appropriate therapy does not only provide exercises to remediate body structure and activity limitations but also identifies adaptive strategies and equipment and environmental modifications to facilitate independence and participation.

Within the medical home, pediatricians can guide families in developing a treatment plan using shared decision making with a focus on enhancing quality of life for the individual with CP.[76] The family's and child's goals are considered as well as what is realistic with the family's schedule and resources. Consideration of the classification of the child's CP (ie, topography; GMFCS, Manual Ability Classification System, and CFCS levels; type of tone abnormality) can help guide management, as do any comorbid conditions, such as visual, hearing, or cognitive impairment. Consultation with developmental-behavioral or neurodevelopmental pediatrics, pediatric physiatry, orthopedics, neuropsychology, or child neurology can often assist with treatment planning. Some medical centers have team clinics for children with CP that may include multiple disciplines and medical specialties, such as developmental pediatrics, neurology, pediatric physiatry, orthopedics, neurosurgery, psychology or neuropsychology, physical therapy, occupational therapy, speech, nutrition, social work, and equipment vendors.

SPECIFIC INTERVENTIONS

Rehabilitative interventions, such as physical therapy, occupational therapy, orthotics, and assistive technology, are the mainstays of management for the motor impairments and activity limitations at the core of CP.[77] These interventions aim to optimize functional independence and participation in life activities and to minimize secondary musculoskeletal deformity but do not treat the underlying brain disturbance.

A diagnosis of CP or a designation of a child as "high risk for CP" based on standardized testing facilitates prompt referrals for CP-specific interventions.[31] Early intervention is crucial, as much of motor learning happens in early childhood, and children with CP reach 90% of their gross motor potential by 5 years of age.[78] Early intervention capitalizes on neuroplasticity, which is the capacity of the brain to adapt structurally and functionally in response to experience and activity, facilitating the possibility of improvement after neural injury.[79] The goals of CP-specific early intervention are to optimize motor, cognitive, and language development, to prevent or slow secondary impairments (eg, hip dysplasia), to minimize the effects of medical comorbidities (eg, vision or hearing loss, malnutrition), and to support parents and caregivers.[31] Therapy is most effective when it is activity based and focused on child-initiated movements.[80,81] Active movement stimulates neuroplasticity more effectively and better promotes development of the neuromotor system than do passive interventions, such as stretching and therapist-initiated movements.[82]

Although more research regarding specific interventions is needed, current evidence indicates that key components of effective early intervention for motor disability include goal-oriented therapy, task-specific training, and environmental enrichment.[80,83,84] Environmental enrichment consists of adapting the living and play environment to make it optimal for motor learning and coaching parents to provide active practice opportunities for movement.[84] Parents and caregivers are taught the typical trajectory of motor skill development and how to identify their child's voluntary attempts to move, as well as how to select toys that promote motor activity and set them up in ways that encourage movement. For example, a motivating toy could be placed in a position such that the child needs to reach or pull himself or herself up to get to it. This setup can gradually be made more challenging and more complex toys can be introduced.

In the United States, Early Intervention (EI) services are available to children ages birth to 3 years with developmental delays and disorders under part C of IDEA. Primary care providers can refer children to their local EI program as soon as there is a concern for developmental delays. A definitive diagnosis is not required. There is variability between and within states with regard to qualifying criteria and the type and amount of services provided. Many children with CP benefit from a combination of part C EI services and outpatient therapies. Guidance for pediatricians regarding EI services is available in the AAP clinical report "Early Intervention, IDEA Part C Services, and the Medical Home: Collaboration for Best Practice and Best Outcomes."[85] At age 3 years, children transition out of EI. Children with CP are often then eligible for school services and therapies through their local school district through an Individualized Education Program (IEP) under IDEA.

The evidence base for the management of CP is rapidly expanding. Novak and colleagues published a systematic review of interventions for children with CP in 2013 with an update in 2020.[86,87] These reviews describe the current state of the evidence for a wide range of interventions for CP using both the World Health Organization's Grading of Recommendations Assessment, Development, and Evaluation evidence rating system[88] and the Evidence Alert Traffic Light System.[89] The traffic light system color codes interventions based on the quality of evidence and effectiveness. Interventions coded green (ie, "do it") have high-quality evidence indicating effectiveness, and those coded red (ie, "don't do it") have high-quality evidence indicating ineffectiveness or harm. Yellow signifies weaker or limited evidence or conflicting findings.

Multiple studies show that therapies are most effective for improving motor function and self-care when they are focused on goals set by the child and family and involve frequent practice of the specific tasks needed for those activities.[80,87] For example, if the family's goal is for the child to feed himself or herself, occupational therapy activities that include specific practice handling eating utensils will be more effective than activities that strengthen the upper extremities more generically. Inclusion of a home program component in which children practice skills they are working on in therapy in the home or other real-life environments is an effective way to increase the intensity of therapy and is associated with improvements in function.[90–92] Although formal therapy typically does not occur daily, families usually work on therapy activities with children between sessions. A treatment program that includes a combination of interventions often leads to the best outcomes.[87]

Some "green light" interventions for improving hand and upper extremity function include constraint-induced movement therapy, bimanual training, and occupational therapy in conjunction with botulinum toxin injections.[87] Constraint-induced movement therapy is an intervention specifically for unilateral CP. The less-affected upper extremity is constrained with a cast or splint while the child engages in functional activities that require use of the affected hand. Bimanual therapy (also known as hand-arm bimanual intensive therapy) focuses on learning to use both hands together to complete tasks. Intensity is key to success with both constraint-induced movement therapy and bimanual therapy.[90] For example, 1 study's protocol consisted of 90 hours of therapy over a 3-week period.[93]

Functional gait training improves walking speed and endurance.[94–97] Use of a treadmill allows for the repeated practice of stepping in a controlled environment with increasing intensity. For children with more significant motor impairment (ie, GMFCS III-IV), gait training using partial body weight support with an overhead suspension and harness system can facilitate the practice of lower extremity weight bearing, stepping, and upright posture. Strength training is effective for improving upper and lower extremity strength, but more research is needed regarding its effectiveness for improving motor function.[97] Similarly, there is good evidence to support hippotherapy (therapeutic horseback riding) to improve balance and posture, although the evidence that it translates to improvements in gross and fine motor function is less clear.[96,98,99]

The systematic reviews[86,87] classify several interventions as "red light" and recommend against their use. Hyperbaric oxygen treatment has not been shown to improve motor function in children with CP and is associated with risks of harm, including hearing loss and pain. The systematic review found that evidence does not support cranial-sacral osteopathy to improve motor function or the use of sensory integration to improve sensory organization or motor skills in children with CP.

Neurodevelopmental treatment (NDT), also known as the Bobath approach, has traditionally been a common mode of therapy for CP. In its original form, NDT was a passive approach in that the therapist positioned and handled the child with the goal of improving tone and postural

control.[100] Increasing evidence indicates that therapies based on motor learning theory, in which the child is actively engaged in motor planning, are more effective than NDT and other passive interventions. Therefore, Novak and colleagues classify NDT as a "red light" intervention, noting that more effective interventions are available to improve motor function.[87,101] This classification is not without controversy, however, and others advocate that more research is needed to clarify the effects of NDT.[102–104] As NDT has evolved over time, variability has developed in how it is defined and practiced, making interpretation and application of the evidence more challenging.[101,105] Some therapists who practice NDT may also incorporate more active therapy strategies. A key point in providing guidance to families is that the emerging evidence most strongly supports interventions that involve promotion of child-initiated movement and participation in functional activities.

ORTHOTICS AND DURABLE MEDICAL EQUIPMENT

Orthotics and adaptive positioning devices help to promote proper skeletal alignment to maintain range of motion and stabilize joints.[77] These items of durable medical equipment (DME) are important in facilitating functional goals, such as mobility and independence in performing activities of daily living.[77] In addition, some types of equipment, such as mechanical lifts, can improve the health of caregivers by preventing back pain.[106] Common examples of orthotics that a child with CP might use include ankle foot orthotics, wrist and hand splints, and thoracolumbosacral orthoses (TLSOs) for scoliosis. Adaptive equipment can include wheelchairs, seating systems for feeding and other activities, standers, and adapted car seats.[56] Home modifications, such as installing ramps, track lifts, or widening doors, are often needed but may be prohibitively expensive.[107] Funds to support this may be available through local grants or Medicaid waivers, but these vary by state.[108]

Some individuals with CP also benefit from assistive technology, which is the use of external items or devices to compensate for functional challenges secondary to disability.[109] Assistive technology can be "low-tech" (eg, grips for silverware, pictures for communication), mid, or "high-tech" (eg, power wheelchairs, speech-generating devices).

Assistive technology devices and other DME can be quite expensive, and there are often insurance limits on how often new equipment can be covered (eg, once every 5 years for wheelchairs). Medical equipment is covered under Medicaid's Early and Periodic Screening, Diagnosis and Treatment benefit, although this requires justification of medical necessity. This can be an area of inequity among children with CP because of variability in insurance coverage for DME and availability of other funding sources.

Primary care providers may be asked to write letters of medical necessity for insurance coverage of these devices and equipment. Primary care providers asked to write such letters can consult with the child's therapists who can assist with documenting the child's specific needs and why each aspect of the equipment is necessary. Where available, pediatric physiatrists or other CP specialists often manage prescriptions for orthotics, wheelchairs, and positioning devices. For higher-tech equipment, such as augmentative communication devices, assessment by an interdisciplinary team including the child and family, therapists, medical specialists, orthotist, rehabilitation engineer, or assistive technology professional is advisable.[110] Factors that need to be considered include what specific device will best meet the child's needs and goals, environmental factors, such as space in the home and family's ability to transport the device, and the availability of training required for the child and family to effectively use the device.[109]

ADAPTIVE RECREATION

Several of the "F-words,"[73] such as fitness, fun, and friends, involve participation in community and recreational activities. Sports participation has multiple benefits for children, including physical fitness, social opportunities, reduction of undesirable behaviors, and the development of independence and teamwork.[111] Youth and young adults with CP tend to be less physically active, participate in fewer recreational activities, and spend less time with friends than those with typical development.[112–114] Multiple factors contribute to this decreased participation, including physical limitations and structural barriers to accessibility, limited social support, and negative attitudes of others in the community.[112]

In addition to occupational, physical, and speech therapies, other therapies and services can help optimize participation and provide opportunities for fitness and fun. Children with CP are often eligible to receive adapted physical education (PE) at school as part of their IEP. Adapted PE provides exposure to sports and recreational activities and introduces skills needed for participation.[115] Therapeutic recreation is a clinical intervention that provides recreational services to people with disabilities or

illness to improve functioning and independence and promote health and wellness.[116] Recreational or occupational therapists can help children explore leisure interests, teach skills needed to participate in games or sports, and assist with obtaining specialized equipment, such as adaptive bicycles. Hippotherapy and aquatic therapy can also help facilitate participation while working on functional motor skills. A number of adaptive sports programs, such as wheelchair basketball and sled hockey, are available to facilitate participation of individuals with physical and developmental disabilities[115] (Table 5).

Pediatric providers can encourage participation by talking to children about what they like to do for fun, helping families explore local opportunities for participation in adaptive sports and other activities, and providing guidance on activities appropriate for the child's condition.[111]

COMPLEMENTARY, ALTERNATIVE, AND UNPROVEN TREATMENTS

The National Center for Complementary and Integrative Health of the National Institutes of Health defines complementary therapies as evidence-based health care approaches developed outside of conventional Western medicine that are used in conjunction with conventional care. In contrast, alternative therapies are not evidence based and are used in place of conventional care.[117] Use of complementary and alternative medicine (CAM) approaches is greater in children with chronic illness and developmental disabilities than in the general population. Rates of parent-reported CAM use in children and adolescents with CP range from 26% to 56%,[118–120] compared with 12% in children overall.[121] More significant functional impairment is associated with a higher likelihood of using CAM among individuals with CP.[118–120]

Guidance regarding CAM use in children is available in the AAP clinical report "Pediatric Integrative Medicine."[117] This clinical report advises that pediatric providers regularly inquire about CAM use and seek evidenced-based information regarding safety and effectiveness of specific CAM therapies to be able to discuss potential benefits and harms with families. Risks to consider beyond bodily harm include time, financial costs, and loss of benefit from other more effective treatments.[122] Providers may decide to recommend a therapy if evidence shows that it is safe and effective or to "tolerate" use of a therapy that does not have good evidence for effectiveness but is safe.[123] For therapies that are effective but carry significant risk, providers may choose to closely monitor for benefits and adverse effects or to discourage use. Therapies that are neither safe nor effective ought to be discouraged[124] (Fig 3). Discussing CAM therapies with an open-minded and nonjudgmental approach while being sensitive to cultural differences can help families to feel more comfortable sharing about their use of such modalities and may help steer families away from unproven, potentially dangerous treatments.[122]

The volume and quality of evidence for CAM treatments is variable. The systematic review of CP interventions by Novak and colleagues[87] includes multiple CAM therapies that fall along the full spectrum of the Evidence Alert Traffic Light System ranging from "green" for hippotherapy to improve balance to "red" for hyperbaric oxygen and cranial osteopathy for improving motor skills. The majority of CAM therapies (eg, melatonin, reflexology, acupuncture, yoga) are classified as "yellow," indicating weaker evidence for or against their use. Consideration of these treatments requires careful consideration of the evidence for benefits and risks on the basis of the child's and family's goals and the

TABLE 5 Adaptive Sports Resources

Adaptive Sports Resources	
American Association of Adapted Sports Programs (AAASP)	http://adaptedsports.org/
National Center on Health, Physical Activity and Disability (NCHPAD)	https://www.nchpad.org/
Cerebral Palsy International Sports and Recreation Association (CPISRA)	https://cpisra.org/
Blaze Sports America	https://blazesports.org/
Move United	https://www.moveunitedsport.org/
Special Olympics	https://www.specialolympics.org/
Specific sports and activities	
Baseball	https://www.miracleleague.com/ https://www.littleleague.org/play-little-league/challenger/
Wheelchair basketball	https://www.nwba.org/
Sled hockey	https://www.usahockey.com/sledhockey
Soccer	https://www.powersoccerusa.org/ https://www.usyouthsoccer.org/programs/topsoccer/
Wheelchair football	https://www.mobility-advisor.com/wheelchair-football.html
Archery	https://physicallychallengedbowhuntersofamerica-inc.org/ http://www.uffdaclub.com/pages/about-united-foundation-for-disabled-archers/
Rugby	https://www.usqra.org/
Skiing	http://ski2freedom.com/en https://www.skicentral.com/adaptive.html
Swimming	https://www.usaswimming.org/home/disability
Outdoor sports and recreation	https://adaptiveadventures.org/

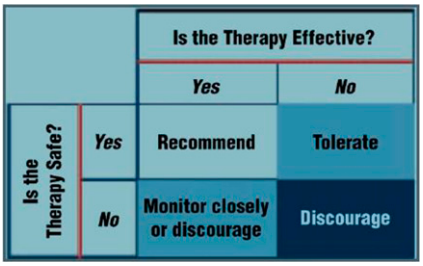

FIGURE 3

A common-sense guide to CAM treatment recommendations. Reprinted with permission from Contemporary Pediatrics. Contemporary Pediatrics is a copyright publication of MultiMedia Medical, LLC. All rights reserved.

targeted outcome. For example, massage is considered a green intervention if the goal is reducing constipation, but the evidence is weaker for improvements in pain, and it is probably ineffective for improving motor skills or reducing spasticity. Similarly, yoga is classified as probably effective for improving muscle strength and flexibility but probably ineffective for improving gross motor skills or reducing pain.

CARE COORDINATION FOR CHILDREN WITH CEREBRAL PALSY

Like all medically complex patients, children with CP benefit from care coordination.[4] Care coordination is a "patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families."[125] Care coordination in medically complex patients improves access to medical care, reduces emergency department visits and hospitalization rates, and improves family satisfaction.[125,126] A recent national study reinforces the need for care coordination in children with CP, showing that "children with CP had a higher odds of unmet need for care coordination than their counterparts without CP."[127] Although ideally based in the primary care medical home, not all pediatricians have the time, training, or staff to provide care coordination for children with medical complexity.[128] Alternate sources of care coordination may be available through outside agencies, including accountable care organizations, insurance companies, children's hospitals, and the state's Title V program for children with special needs.[128]

Care coordination aims to support communication and synchronization with all of the patient's medical subspecialists, mental health providers, therapists, nursing providers, school services, and other community-based services, with the patient's and family's goals in mind.[128,129] Ideally, care coordination not only improves medical care but also anticipates potential medical complications and provides care that is "proactive rather than reactive."[128] Because of the potential expense, range of needs, and multiple systems of care, care coordination is best provided through an interdisciplinary team.[23,129,130]

Several models of care for children with medical complexity can be used for children with cerebral palsy.[4,129,131,132] Training modules and recommendations are available to guide practices to optimize care coordination.[129,131,133,134] A care plan and care maps can help coordinate patient and family goals and patient needs, and are a helpful way of organizing care and communicating to other providers.[128–130]

COGNITION AND LEARNING

One of the associated comorbidities of CP is the possibility of intellectual developmental disorder (intellectual disability) and specific learning problems.[135] Intellectual developmental disorder is defined as a combination of reduced intellectual functioning (2 or more standard deviations below the mean on "psychometrically valid, comprehensive, culturally appropriate, psychometrically sound tests of intelligence") as well as limitations in adaptive functioning "in comparison to an individual's age-, gender-, and socioculturally matched peers."[136] Information from population registries shows that almost 50% of children with CP have an intellectual developmental disorder, with 28% having a severe intellectual disability.[137] Estimating the cognitive level of the individual child is important because it is used to plan for education, later employment, and guardianship and as an eligibility criterion for disability funding.[138] In addition, intellectual functioning has been used as a predictor for whether a child or adolescent will be able to live independently.[137]

Concerns have been raised about the accuracy of IQ testing in children with CP because of the associated fine motor, verbal, and visual impairments that often coexist in these children.[138–140] Yin Foo et al, in their systemic review of IQ assessments of children 4 to 18 years of age with CP, offer an algorithm to consider which IQ tests to use considering the patient's GMFCS level, communication ability, and/or visual impairment.[138] They also recommend a global approach on how to view IQ in children with CP, getting additional input from a variety of sources, including parents and teachers. A systematic review of developmental testing in infants and children younger than 2 years similarly looks at tests for younger children with motor disabilities.[139] The authors recommend a number of "assessment tools" for infants and children with motor impairments that adjust for those impairments and allow for accurate test results.[139] In children with CP, adaptive functioning could be impaired because of motor deficits, especially in children with higher GMFCS levels, which may further interfere with an accurate assessment of intellectual level.[140] Because many individuals with CP do not have cognitive challenges, it is important not to assume cognitive

impairment on the basis of an individual's motor or speech impairment.

Children with CP, with or without intellectual developmental disorder, may have speech and language or fine motor impairments that challenge their ability to learn. Children with CP can have specific learning problems, including problems with reading and mathematics.[141] Problems with fine motor functioning, word decoding, and working memory may contribute to delays in arithmetic abilities in children with CP.[141,142] Difficulties in phonological processing and "visual-spatial relationships" were associated with delays in reading (decoding) and spelling in a small study of children with CP who did not have language or communication delays.[143] "Visual-perceptual problems, attention problems, and executive functioning" issues that have been described in children with cerebral palsy can affect academic functioning.[144]

An innovative idea is teaching reading to children with CP with speech impairment using augmentative and alternative communication (AAC) devices. A recent review examined the use of AACs to learn single word reading in a mixed group of children with disabilities, including CP. This review showed that use of an AAC improved acquisition of single word reading.[145] Novak et al, in their review of interventions for children with CP, support the use of AACs to teach literacy[87] (see Communication section for further discussion of the use of AACs).

Various factors are important in school success for a child with CP. The importance of family collaboration and preparation of the school for the child's needs is critical. Families are most knowledgeable about their child's needs as well as approaches that work best for their child. Communication and collaboration among those therapists who treat or have treated the child improves success. Focusing on and using a child's strengths and abilities ought to be emphasized.[146]

Pediatricians play an important role in assisting their patients and families when it comes to school services and placement.[147,148] The federal legal mandate through IDEA in the United States is that all children are to be provided free and appropriate public education in school, inclusive of children with disabilities, in the least restrictive environment. After a school-provided evaluation, and in conjunction with the family and patient goals, an IEP is developed that includes type of class placement, therapies to be provided, transportation, accommodations, and a transition plan by midadolescence.[147] Some school services may be provided under section 504 of the Rehabilitation Act of 1975 rather than the IEP. The IEP recommends class placement and therapies, whereas the "504 plan" provides other services, including reasonable accommodations and medically related services—for example, asthma therapy and mobility assistance. Generally, the pediatrician or other specialist completes a "504 form" regarding medical diagnoses and needs for a patient to obtain these other services. Pediatricians can consider reviewing a patient's IEP with the patient and family to advocate that services appropriate for the individual patient with CP are received in the least restrictive environment.[148] Pediatricians can refer to recent AAP statements for further information.[147,148] Templates for letters to request school evaluations by pediatricians as well as a discussion of how to interpret test scores are available through the AAP.[148] Consultation with a developmental pediatrician, psychologist, neuropsychologist, intervention specialist, pediatric physiatrist, or neurologist may be helpful in assisting the pediatrician in understanding the strengths and areas of challenge for a patient with CP. These specialists, and occasionally an educational lawyer or legal advocate, can assist in obtaining appropriate services.

COMMUNICATION, SPEECH, AND LANGUAGE DELAY

Communication problems are common in children with CP; 60% to 80% of children with CP have some type of difficulty communicating, and 25% are nonverbal.[137,149,150] Children with CP who have communication problems may have problems with speech (the way words are said), language (the understanding of words and use of words or symbols in the case of sign language), or both.[150] As with any child with a communication problem, a full evaluation by a speech pathologist will help determine what aspects of communication are delayed and need therapy. Classification systems can identify levels of ability and be paired with a full speech evaluation.[151]

Like the GMFCS classification for motor problems in children with CP, a number of classification systems have been developed for children with CP, including the Communication Function Classification System (CFCS).[14] The CFCS has 5 levels, with level V being the most impaired. It focuses on expressive and receptive communication abilities and whether familiar or unfamiliar individuals understand the communication.

It is important to determine the etiology of the communication problem to determine the appropriate therapies. Dysarthria, a motor disorder of speech, can affect 50% of children with CP and can interfere with the intelligibility of speech, causing a significant speech delay.[149] Many children with dysarthria will have good receptive language abilities that may be underestimated because of the lack of intelligibility. In 1 study, parents of

16- to 18-year-old youth with bilateral CP and speech impairment noted that 75% understood their child's "conversations and instructions."[152] Children with CP who have greater physical disabilities (GMFCS IV and V), dyskinetic CP, or epilepsy are more likely to have communication difficulties.[137,152] Intellectual developmental disorder, hearing loss, fine motor delay, and social delays are also common problems in children with CP and are factors associated with language delay.[152,153]

The inability to communicate negatively impairs one's ability to interact in social settings and participate in education and decreases quality of life.[149] Therefore, it is important to identify speech problems in children with CP early and initiate intervention promptly.[149,150,151]

Pediatricians can refer children with CP for speech and language evaluations and therapy as soon as a delay is detected. If not completed earlier, a speech evaluation can occur at the age of 2 years if there is suspicion of speech or language delay.[151] A review of the literature did not find high-grade evidence for a particular speech intervention at an early age (younger than 2 years) geared for infants who have been found to have a medical history or physical findings suggestive of CP.[154] Early language therapies in infants to improve early language development are recommended and ought to involve the parents and caregivers as part of therapy team. Although prediction of which children with CP will develop speech and language delay is difficult, 1 study showed that 73% of children with CP who did not speak at age 2 years did not speak at all at age 4 years.[149] Another study showed that cognitive and speech delay at age 2 years predicted later "speech impairment."[152]

Therapies for children with CP who have difficulty communicating can use a "total communication" strategy.[150,155] This strategy is individualized for every child. Strategies include enhancing communication with verbal output and speech, facial expression, body movements, and sign language, considered "unaided communication" as well as using "aided communication" using AAC.[150,155] AAC includes a wide variety of tools, from very simple tools that are pictorial (symbols and pictures) to electronic tools, including those with vocal output. A multidisciplinary evaluation is important to determine which AAC will benefit an individual child. Input from an occupational and/or physical therapist can be beneficial in identifying positioning strategies to optimize the child's access to the device. Ongoing monitoring and changing of the AAC used is important as a child develops.[150] AACs can enhance the topics and extent of communication of children with CP. In 1 study of 16- to 18-year-olds with bilateral cerebral palsy, 75% of those with the most severe speech impairment had an AAC; however, most only used this device at school. Assessing the family's ability to communicate with their child and what methods of communication work best for that family is important in determining if and what type of AACs can be provided for the home.[152]

BEHAVIOR AND MENTAL HEALTH

Behavioral and mental health symptoms and disorders are prevalent among children with CP and can affect participation in social and community activities and quality of life. Reported rates of behavioral and mental health problems vary depending on study methodology, ranging from approximately 22% to 60%, but are consistently higher than those in the general population, with many children having symptoms of more than 1 disorder.[156,157] Commonly reported behavioral symptoms in children and adolescents with CP include inattention, hyperactivity and impulsivity, disruptive behavior, anxiety, and depression.[156,158–161] The prevalence of autism spectrum disorders also appears to be greater in children with CP (approximately 6% to 9% or higher) than in the general population.[162–164]

Multiple factors contribute to this increased risk of behavioral and mental health symptoms, including the underlying brain disturbance, pain and physical difficulties,[161] and stress related to challenges with participation in community and social activities.[165,166] Adolescents with CP may have a less positive body image than peers, which can affect their well-being.[167] Teasing and bullying related to the disability can also adversely affect emotional adjustment.[168]

Most research suggests that comorbid intellectual developmental disorder[156,160] is a risk factor for behavioral disturbances among individuals with CP, as are communication disorders,[161] although there is some variability between studies. Studies have also found conflicting results with regard to the role of the functional severity of the CP in behavioral and mental health disorders. Emotional symptoms can be more challenging to recognize and evaluate in individuals with greater functional impairment; therefore, fewer data are available on their prevalence in this group. Some investigators have excluded or omitted data on children with the most severe motor impairment as they were unable to participate in psychiatric interviews, or parents responded that the behavioral scales used for the study were not applicable to their children.[158–160]

Although mental health disorders are more common in children with

CP than in typically developing children,[156,157] they are often more difficult to diagnose, especially in those with more significant physical disability and in the presence of comorbid intellectual developmental disorder. Challenging behaviors may be a means of expressing physical discomfort, fatigue related to poor sleep, or distress related to a change in routine in an individual with limited verbal skills.[169] These behaviors may be the result of frustration secondary to communication impairment rather than an underlying mental health condition.[159] Children with CP may also have difficulty verbalizing feelings related to anxiety or depression, and these conditions may manifest instead as behavioral outbursts or changes in sleeping and eating patterns. It is important to avoid "diagnostic overshadowing" in which symptoms, such as fatigue, are attributed to CP and comorbid mental or physical health conditions are overlooked. Review of the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)*[136] criteria and consideration of what is developmentally appropriate for the child's functional level are important in determining whether a diagnosis of a behavioral condition in addition to CP is appropriate. Interdisciplinary assessment can be particularly valuable in evaluating for autism in the presence of CP.

Ideally, assessment for pediatric mental health conditions includes an interview with both the child and parents. In a child with CP who has significant comorbid cognitive or communication impairment, clinicians often need to rely more on family and caregiver report and on obtaining direct behavioral observations. Screening and assessment tools commonly used to evaluate behavioral disorders can be more difficult to interpret in children with CP as many of the more readily available behavioral rating scales are not designed to measure symptoms in children with neurodevelopmental disabilities.[156,158] However, when interpreted with caution and in the context of the child's overall developmental presentation, these can be useful to quantify behavioral symptoms and track change in response to interventions as well as to obtain data on behavioral symptoms from informants not present in a clinical encounter, such as teachers and babysitters. Functional behavioral assessment, which examines antecedents and consequences of a behavior, is valuable in determining the function a behavior is serving for the child (eg, attention seeking, task avoidance, communication) to guide development of an intervention plan.

The ICF and the 5 F-words[73] provide a helpful framework to approach mental health. Encouraging *friendships, family* relationships, and participation in recreational activities (ie, *fun)* support mental wellness. Pediatricians can talk to youth with CP about their goals and hopes for the *future* and promote self-determination as youth with CP and other chronic conditions associate self-determination (ie, independence, goal achievement, believing in oneself, perseverance) with having a good quality of life.[170] Management of behavioral challenges in children with CP begins by addressing physical symptoms, such as pain and insomnia (ie, *fitness*), and skill deficits, such as communication and social skills (ie, *function*), which may be triggering or exacerbating behaviors. This may involve medical interventions or referrals for developmental therapies to work on skill development.

Specific treatments for behavioral and mental health disorders are similar to those in typically developing children and adolescents: behavioral or psychotherapy and psychotropic medications. Parenting interventions that teach parents strategies for managing disruptive behaviors are an evidence-based treatment of behavioral and emotional problems in children and have shown benefit for families of children with CP.[171] The systematic review by Novak et al[87] classifies Stepping Stones, Triple P, and Acceptance and Commitment Therapy (ACT) as green light interventions for improving child behavior and reducing parenting stress. Stepping Stones is a parent training program that is a version of the Positive Parenting Program (Triple P) geared toward families of children with developmental disabilities. Acceptance and Commitment Therapy is a type of cognitive behavioral therapy that focuses on increasing psychological flexibility and enhancing a caregiver's ability to use behavioral strategies in stressful situations.[171] Although some interventions such as cognitive behavioral therapy have not been well studied specifically in individuals with CP, there is high-quality evidence in other populations, and they are likely to be effective for many individuals with CP as well.[87]

For children requiring pharmacologic intervention, medications can be chosen on the basis of treatment guidelines for the diagnosed behavioral or mental health disorder or target symptoms. Very few studies have specifically examined the use of psychotropic medications in this population. Children and adolescents with CP may be more prone to side effects from these medications that act on the central nervous system, as they are often prescribed multiple other medications for comorbid conditions with potential drug interactions.[165] As with other developmental disabilities, medication management is approached cautiously using the following guidelines: Start low. Go slow. Avoid polypharmacy.

Pediatricians can support mental health and resilience in children and

adolescents with CP by checking with patients and families about how they are coping and screening for emotional and behavioral conditions, such as depression. Although specialist consultation from psychology, developmental behavioral pediatrics, or psychiatry may be needed to assist with formal assessment and management, the PCP plays an important role in recognizing behavioral and mental health symptoms and in assessing for sources of physical discomfort or fatigue (eg, constipation, gastroesophageal reflux disease, musculoskeletal pain, dental pain, ear or sinus infection, obstructive sleep apnea, or other sleep disturbance) that may be contributing to the behavioral presentation. The American Board of Pediatrics' Roadmap Project provides resources to help pediatricians promote resilience and emotional and mental health in their patients with chronic conditions and their families.[172]

EPILEPSY

Epilepsy commonly coexists with the motor disturbances of CP. Prevalence rates of epilepsy in children with CP are between 35% and 62%.[39] Risk factors for epilepsy in CP include the presence of neonatal seizures and structural brain abnormalities.[173] Despite the high concurrence, little research has examined the interplay between these 2 disorders of the brain. Seizures may present subtly with apnea, staring, posturing, developmental regression, or sleepiness, so clinicians can ask about such symptoms. Parents of children with CP identified seizures as 1 aspect of their children's care that was most stressful[174] and contributed to lower quality of life.[175] Some of this stress can be mitigated through the use of individualized "seizure action plans."[176]

Overall, the treatment of epilepsy in the patient with CP is similar to that of other patients, and often undertaken in partnership with a neurologist. However, treatments for epilepsy, such as antiseizure medication, may affect treatments for CP and vice-versa. There is a possibility of drug interactions and the possibility of additive risk for the child. For example, a child with CP may be at risk for low bone mass because of immobility, which could be made even worse by the use of several commonly used seizure medications, including valproate and oxcarbazepine, which interfere with bone accrual by altering calcium and vitamin D metabolism or by direct effect on bone tissue. The ketogenic diet, also used for refractory epilepsy, can reduce bone density.[177]

On the other hand, antiseizure medications may have positive effects on manifestations of CP. Clobazam is a benzodiazepine that is commonly used for epilepsy and has the added benefit of reducing tone in children with spasticity.[178] Other benzodiazepines, such as diazepam, are more commonly used for spasticity, but can also improve seizure control.[179] Gabapentin is another anticonvulsant that may also reduce spasticity, dystonia, and chronic pain in children with CP.[180] Conversely, there is sometimes concern about using baclofen for spasticity in children with epilepsy because it may lower the seizure threshold, although this is routinely used concurrently with antiseizure medications.[181]

SENSORY IMPAIRMENTS

Individuals with CP have increased rates of visual impairment and hearing loss, which can have functional consequences. For example, challenges hearing the teacher in a classroom or limitations in accessing written or visual materials can interfere with learning, and difficulties seeing and hearing peers can affect social interactions. Addressing correctable problems or providing accommodations as early as possible can improve learning, school performance, and social participation.

Visual Impairment

Children with CP frequently (50% to 90%) have visual impairment and other ophthalmologic conditions, including refractive errors, strabismus, nystagmus, amblyopia, and cortical visual impairment, sometimes termed cerebral visual impairment (CVI).[182,183] Individuals with more significant motor impairment tend to have more frequent and more significant visual and oculomotor deficits.[183] Vision problems in children with CP may be underrecognized and may be difficult to evaluate in patients with a greater degree of motor and communication impairment without specialized techniques and technology, such as visual evoked potentials.[183,184]

Because ophthalmologic interventions are most effective when initiated early,[56,185] formal ophthalmologic evaluation early in childhood, in addition to the usual vision screening recommended by *Bright Futures,* can be valuable for children with CP. Some children require ongoing ophthalmologic monitoring based on initial examination findings and individual risk factors (eg, prematurity). Young children or those with cognitive or language difficulties may need specialized assessments to determine visual acuity.

More than half of children with CP have CVI.[182,184] CVI is caused by injury to or abnormal development of the visual areas in the brain, which are commonly affected by lesions and injuries that cause CP.[182]

These include hypoxic-ischemic injury, periventricular leukomalacia, hydrocephalus, central nervous system infections, traumatic brain injury, and congenital brain malformations.[184,186]

The visual impairment in CVI can range in severity from blindness to normal or near-normal visual acuity with deficits in higher-level visual perception (ie, cognitive visual dysfunction).[184,186,187] Specific manifestations in an individual depend on the areas of the brain affected. For example, abnormalities in the primary visual cortex in the occipital lobe affects acuity, visual fields, and perception of contrast and color, whereas disturbances of the optic radiations can cause visual field deficits which can hinder stair negotiation, self-care activities, and academic performance.

The diagnosis of CVI is primarily clinical. Visual impairment that is not explained by the ocular examination, especially in children with a history of a brain disturbance, is suggestive of CVI. The eye examination may be structurally normal. However, CVI can occur comorbidly with eye conditions (eg, strabismus, retinopathy of prematurity), so examination by an ophthalmologist with expertise in neuro-ophthalmology is important when CVI is suspected. Parent and caregiver description and observation of the child's visual behaviors can be very helpful in making the diagnosis. Table 6 lists some visual characteristics and behaviors that can be associated with CVI. In evaluating for CVI, a multidisciplinary approach is recommended to optimally assess visual function and determine management.[186,187] Involved disciplines may include ophthalmology, optometry, neurology, occupational therapy, neuropsychology, teacher of the visually impaired, and radiology. Difficulties with visual perception may not be recognized until a child reaches school age and can participate in standardized testing.[182]

TABLE 6 Visual Characteristics and Behaviors in Cortical Visual Impairment

Visual Characteristics and Behaviors
Degree of vision loss unexplained by ocular findings
Fluctuating level of vision
Improvement in vision over time
Poor visual fixation
Preference for staring at lights (but some may have photophobia)
Better vision for moving versus stationary objects (but may have impaired perception of movement in some cases)
Better vision in familiar environments
Distinct color preferences
Pronounced head turns to search for objects (possibly to make use of residual peripheral vision)
Poor depth perception
Difficulty differentiating between background and foreground visual information
Difficulty maintaining visual attention
Visual field deficits
Flicking fingers in front of the eyes for self-stimulation

Courtesy of K Steingass, American Academy of Pediatrics, PREP DBPeds Self-Assessment.

In children with CVI, vision often improves over time, especially from 1 to 3 years of age, because of visual neuroplasticity.[184,187] This improvement occurs more readily in earlier onset lesions. Despite improvement, most individuals continue to have some degree of visual impairment.

Hearing Loss

Hearing loss also occurs at higher rates (4% to 13%) in individuals with CP than in the general population, although it is less common than visual problems.[188,189] As with CVI, there is overlap in the etiologies for CP and those for sensorineural hearing loss.[188,189]

Auditory neuropathy, also known as auditory dyssynchrony, is a specific type of sensorineural hearing loss that results from dysfunction in the inner hair cells, neurons of the spiral ganglion, or the auditory nerve.[190] The cochlea appears to receive sounds normally, but processing of the signal from the cochlea to the auditory nerve or along the auditory nerve is abnormal. Multiple neonatal risk factors associated with CP have been associated with auditory neuropathy, including prematurity, hypoxia, hyperbilirubinemia, and prenatal or neonatal infections.[190,191] Clinically, the hearing loss associated with auditory neuropathy can be fluctuating, with particular difficulty with speech perception in background noise. It can be more challenging to manage than other forms of hearing loss, but many children do receive benefit from hearing aid amplification or cochlear implantation.[190] It is important to be aware that screening using otoacoustic emissions will miss hearing loss attributable to auditory neuropathy as it only assesses the function of the peripheral auditory system (outer ear, tympanic membrane, middle ear) and the outer hair cells in the cochlea. For this reason, the Joint Committee on Infant Hearing recommends that the hearing of infants in the NICU be assessed by auditory brainstem response because of the increased risk of auditory neuropathy in this population.[192]

The AAP clinical report, "Hearing Assessment in Infants and Children: Recommendations Beyond Neonatal Screening," recommends that children who have speech and language delays as well as those who have a history of risk factors

for delayed-onset or progressive hearing loss be referred for formal audiologic assessment at least once by age 24 to 30 months even if there are no clinical concerns.[57] Many children with CP have speech delays or 1 or more of these risk factors (Table 7). Some children with CP may require a sedated auditory brainstem response procedure for adequate evaluation if their motor or other impairments interfere with their ability to participate in behavioral audiometry.[57]

PULMONARY PROBLEMS

Children with CP often present to their pediatrician with respiratory symptoms, ranging from mild upper respiratory infections to severe acute and chronic lung disease. In most cases, mild illness can be treated with standard supportive care as in any other patient. However, pulmonary problems are the leading cause of hospitalization[193] and death[194,195] for patients with CP. Abnormalities may exist at multiple levels related to the motor problems of CP, comorbid conditions, or the underlying etiology.[196]

The nose and oropharynx provide an important filtering function as air is breathed in and out. Approximately 5% of patients with CP have a tracheostomy[197] which bypasses this filter; such patients are, therefore, at higher risk for respiratory tract infection. A tracheostomy may be placed in patients with CP to bypass upper airway obstruction (such as with tracheomalacia), or to allow for mechanical ventilatory support. These are particular issues for children born preterm, but any patient with significant CP (GMFCS IV or V) might be prone to upper airway obstruction because of diminished airway tone.

TABLE 7 Risk Factors for Delayed-Onset or Progressive Hearing Loss in Children with CP

Risk Factors for Delayed-Onset or Progressive Hearing Loss
Neonatal intensive care >5 d
Mechanical ventilation
Extracorporeal membrane oxygenation (ECMO)
Exposure to ototoxic medications (eg, gentamycin, tobramycin, furosemide)
Hyperbilirubinemia requiring exchange transfusion
In utero infection (cytomegalovirus, rubella, syphilis, toxoplasmosis)
Postnatal meningitis

Courtesy of K Steingass, American Academy of Pediatrics, PREP DBPeds Self-Assessment.

Swallowing issues are extremely common in CP, particularly among those with more significant involvement, although dysphagia can be present at any level of function.[198] In addition to the usual symptoms of coughing and choking, aspiration can be silent. This can lead to chronic lung inflammation and infections, often with organisms heavily resistant to antibiotics.[199] The lungs are also vulnerable to aspiration from gastrointestinal reflux, which is highly prevalent in patients with CP, particularly among those receiving tube feeding.[200] The presence of reflux is an independent predictor of an increased risk of respiratory illness requiring hospital admission.[201]

Children with CP may have bronchospasm attributable to innate allergy or asthma or underlying chronic lung disease of prematurity or as a reaction to oral or gastric secretions. Standard short-acting therapies (β2 agonists) and anti-inflammatories (inhaled corticosteroids) are used.

An important component of lung health is the ability to clear secretions from large and small airways through effective coughing. This is often impaired in patients with CP because of muscular weakness and skeletal deformities, especially progressive scoliosis.[202] Hypoventilation is more common in those with a greater degree of motor involvement because of muscular weakness and skeletal deformities that decrease the efficiency of gas exchange. The overall level of gross motor function is closely tied to the neuromuscular performance of the respiratory system.[203–205]

At the alveolus, there may be abnormal gas exchange because of chronic lung infections, bronchiectasis, or bronchopulmonary dysplasia related to preterm birth. These can lead to both inadequate oxygenation and ventilation with chronic hypoxia and/or hypercarbia.

Abnormalities of the pulmonary vasculature may interfere with transfer of oxygen between the alveoli and pulmonary circulation. Pulmonary hypertension, a microvascular problem, may be prevalent in patients with CP who were born preterm, have underlying heart disease, or are affected by sleep-disordered breathing.[202] By contrast, pulmonary embolism (PE) is an obstructive problem of larger blood vessels, usually originating from a deep vein thrombosis (DVT) in the legs. Although patients with significant motor impairments might be expected to have a high rate of DVT or PE because of immobility, this has rarely been reported.[206,207] The true risk of PE in this population is unknown. There is currently no recommendation to screen asymptomatic patients with CP for DVT, but investigation is reasonable in the setting of clinical symptoms, such as unilateral limb pain or swelling, or unexplained chest pain or hypoxia. The presence of a central venous catheter is a particular risk factor.[208] Some authors recommend instituting DVT prophylaxis or consulting hematology for hospitalized patients with CP and additional risk factors for thrombosis.[209]

Pulmonary Assessment

The pulmonary assessment in patients with CP is often challenging. Many patients cannot actively participate with the physical examination well enough to allow for adequate auscultation of the lungs. General inspection of the patient is often more revealing and might include evidence of tachypnea, upper airway obstruction, excessive oropharyngeal secretions, and accessory muscle use. Pulse oximetry can usually be performed in the office setting and can augment the physical examination. It is helpful to know what a particular patient's oxygen saturation is when he or she is healthy as a comparison for an acute illness. Chest radiography is often necessary to assess acute respiratory problems, so having a baseline film for comparison can be helpful. Pulmonary function testing is helpful but is often unobtainable in patients with CP because of age, difficulties with motor control, or cognitive ability.

Sleep-Disordered Breathing

There may be an abnormal respiratory drive (central sleep apnea) and/or obstruction of the airway (obstructive sleep apnea), particularly among those who are significantly affected by CP or have epilepsy.[210] Medications that decrease alertness or airway tone may increase the risk of sleep-disordered breathing (SDB). These include medications commonly used in patients with CP to treat pain, spasticity, seizures, or behavioral problems.

Recognition of the potential for SDB is the first step toward management and may lead the pediatrician to obtain a thorough history for symptoms that suggest the condition. Patients may present with obvious signs, such as observed apneas or choking while sleeping, or with vague signs, such as daytime sleepiness, morning headaches, or worsening cognitive performance. Stertor or stridor while awake might be investigated with a lateral neck radiograph or laryngoscopy for assessment of the adenoids. Intranasal steroids or oral Montelukast may decrease obstruction enough to prevent the need for airway surgery.

When SDB is suspected, overnight polysomnography can be performed. Standard methods of interpretation are used. As in other patients, people with CP and SDB can be treated with airway procedures (tonsillectomy, adenoidectomy, uvulopalatopharyngoplasty, glossopexy, tracheostomy), or positive pressure (continuous positive airway pressure [CPAP] or bilevel positive airway pressure [BiPAP]). In extreme cases of central sleep apnea, nocturnal mechanical ventilation may be instituted via BiPAP or tracheostomy.

Prevention of Pulmonary Complications

Immunization against preventable respiratory diseases is of paramount importance to maintaining optimal pulmonary health. Unless there are medical contraindications, children and adults with CP should receive the standard immunizations on the standard schedule, especially those against pertussis and pneumococcus, in addition to coronavirus disease 2019 (COVID-19) vaccine and the annual influenza vaccine. Close contacts of the patient with CP may also be immunized to "cocoon" the individual.[211] Patients with chronic lung disease are eligible to receive additional doses of pneumococcal vaccines per Centers for Disease Control and Prevention guidelines.

Prevention of infection and aspiration is important to maintain good pulmonary health. In addition to the immunization strategies above, patients and parents ought to be counseled to avoid tobacco smoke and other environmental exposures that could exacerbate an underlying respiratory condition. A recent study suggested that dental care in particular reduced the risk of pneumonia in patients with CP.[212] The risk of aspiration can be reduced by manipulating textures or size of the oral bolus, decreasing salivary volume through the use of anticholinergic medications or salivary procedures,[213] or medical or surgical options to decrease gastroesophageal reflux, such as fundoplication or postpyloric feeding[214] (see Nutrition, Growth, and Gastrointestinal Problems section for more details).

Patients with a tracheostomy are prone to chronic respiratory infections, especially with highly resistant organisms. Efforts to keep the tracheostomy and tube clean are important, but all will eventually be colonized.[215] In a small series, prophylactic inhaled antibiotics targeted to resistant organisms was shown to reduce the frequency of pneumonia in children with CP and a tracheostomy.[216] This protocol has not been rigorously studied, and different antibiotics and different regimens have been suggested.

The role of orthopedic interventions in maintaining respiratory function is controversial. Despite the fact that scoliosis and chest wall deformities are a major cause of respiratory problems, surgical correction has not been definitively shown to improve pulmonary function nor reduce respiratory morbidity in patients with CP.[217] However, parents of patients with CP report that prevention of cardiopulmonary problems was their number 1 goal for scoliosis surgery, that a large proportion perceived improved respiratory status following surgery, and that they were satisfied with their decision to have their child undergo surgery.[218]

Artificial means of mucus clearance are especially important for patients with reduced ability to cough or to handle pulmonary mucus, oral secretions, or refluxed material once it reaches the oropharynx. Chest physiotherapy, including positioning, hand percussion, and vibration are effective and easily taught and do not require specialized equipment unless suctioning is also needed to clear the airway.[219] High-frequency chest wall oscillation therapy by means of a vibrating vest may be used and is usually well tolerated.[220,221] Newer devices, which insufflate and exsufflate the lungs through a mask to promote cough (the "cough assist"), frequently used in patients with neuromuscular disorders,[222] can also be used in patients with CP with deficient airway clearance.

Patients with respiratory insufficiency or failure as a result of intrinsic or restrictive lung disease may be treated with mechanical ventilation. Ventilatory support may be applied via nasal or full face mask by BiPAP (noninvasive ventilation), or through a tracheostomy by traditional ventilator (invasive ventilation). Because the addition of home mechanical ventilation is a major undertaking for a family, the decision to commit a patient with CP to this therapy is not made lightly.[223] Careful consideration of the proposed benefits, risks, and burden to the individual and family is needed. The choice between BiPAP, tracheostomy or ventilation, or forgoing artificial ventilation is individualized and based on the individual circumstances of the patient, goals and values of their family, and capabilities of the home and health care system. The involvement of a palliative care specialist to help the family, pulmonologist, and pediatrician examine the benefits and burdens of the proposed intervention is desirable.[224]

SLEEP

Sleep problems, such as insomnia and SDB, are common in children with CP, affecting 20% to 40% of patients.[225,226] Children with CP are more likely to have parent-reported sleep problems than typically developing siblings,[227] peers,[228–230] or children with other motor disabilities.[231] Sleep problems are important to recognize and address, because they affect daytime functioning[231] and are associated with lower quality of life in children with CP.[232] Children's sleep problems disrupt parental sleep, especially for children with CP who may frequently require caregiver intervention during the night.[231] This sleep disruption has been associated with increased rates of maternal depression.[228]

As in typically developing children, the most common type of sleep disturbance in children with CP is difficulty initiating and/or maintaining sleep (insomnia).[225,226,232] SDB is also relatively common and covered in more detail in the pulmonary section of this report.[219,232,233]

Across studies, pain is significantly associated with sleep problems.[226,231,233] Other medical comorbidities that interfere with sleep include epilepsy, visual impairment affecting circadian rhythm, gastroesophageal reflux disease (GERD), constipation, and sialorrhea.[225,228,229,233] Some studies suggest that sleep problems are more common in individuals with a greater degree of motor impairment[225] and in older children,[226] but sleep challenges affect children with CP of all ages and GMFCS levels.[234] For younger children and individuals with more mild CP, sleep problems tend to relate more to the sleep environment, bedtime routines, and behavior, whereas for those with a greater degree of motor impairment, positioning, pain, pressure care, breathing, and GERD are more significant factors.[234] Parent-reported sleep problems correlate with parent-reported behavioral problems.[225,230] This relationship is likely bidirectional in that insufficient or poor-quality nighttime sleep can adversely affect daytime behavior, and behavioral disorders are commonly associated with sleep challenges.

Evidence for specific treatment of insomnia in children with CP is limited, but information is available regarding management of sleep problems in children with neurodevelopmental disabilities more broadly. Because of the significant effects of medical comorbidities on sleep in children with CP, optimizing management of these conditions (eg, treating GERD, pain, and seizures, addressing obstructive sleep apnea) is a first step in improving sleep.[235] Pediatricians can provide guidance to caregivers on sleep hygiene, such as maintaining a consistent bedtime routine and ensuring that the environment is conducive to sleep.[235,236] If sleep problems persist, behavioral strategies (eg, bedtime fading, bedtime pass) may be implemented (Table 8). Evidence suggests that these strategies, which are commonly used in typically developing children, are feasible and have effectiveness in children with neurodevelopmental disabilities but may require modification for the individual child.[235–237] Although pharmacotherapy is commonly used for sleep in children with neurodevelopmental disabilities, the evidence base for this is quite limited.[235,236] Melatonin is the most studied pharmacologic agent in this population with findings suggesting that it is safe and effective for improving sleep-onset latency and total sleep time.[235,236,238] The systematic review by Novak and colleagues classifies melatonin as a

TABLE 8 Behavioral Sleep Interventions

Behavioral Sleep Interventions	Description
Extinction ("crying it out")	Parents put the child to bed and ignore until morning (but monitor for concerns for safety or illness).
Graduated extinction ("sleep training")	Parents put the child to bed and ignore crying and tantrums for a predetermined period of time before briefly checking on and reassuring the child. The time between checks is gradually increased. The time between checks should be determined based on the child's temperament and the parents' tolerance for crying.
Fading of parental presence	Parents put the child to bed and gradually fade their proximity to and interactions with the child during sleep-onset every few nights. For example, the parent can transition from lying next to the child to sitting in a chair next to the bed and progressively move the chair further from the bed every few nights until they are no longer in the room.
Scheduled awakenings	After establishing the baseline timing and number of night awakenings, parents wake the child up 15–30 min before the typical awakening and follow their typical response to spontaneous awakenings. The scheduled awakenings are then gradually faded out by increasing the time between them.
Positive routines	Parents develop a consistent bedtime routine of calm activities to establish a behavioral chain leading up to sleep onset and promote appropriate sleep associations. Use of a transitional object such as a blanket or stuffed animal can help promote appropriate sleep associations.
Bedtime pass	Parents provide the child with 1 or 2 tokens (the bedtime "pass") that can be turned in for 1 request or contact with a parent after bedtime. If the child does not use the bedtime pass, he or she can turn it in for a positive reinforcer in the morning
Bedtime fading	The designated bedtime is temporarily delayed until it coincides with the child's usual onset of sleep. The bedtime is then gradually moved earlier. If the child fails to fall asleep as expected, he or she is taken out of bed briefly before put to bed again.

Courtesy of K Steingass, American Academy of Pediatrics, PREP DBPeds Self-Assessment.

"yellow" (probably do it) intervention.[87]

NUTRITION, GROWTH, AND GASTROINTESTINAL PROBLEMS

Feeding problems and adequate nutrition are often a major challenge for children and adolescents with CP,[4] particularly in children with a greater degree of motor impairment.[239,240] Feeding difficulties may result from coordination problems at the oral and pharyngeal levels that result in dysphagia, excessive time needed for feeding, gastrointestinal tract motility problems, vomiting, risk for aspiration, dental issues, and maladaptive behavioral responses to feeding.[241] Inadequate nutrition leads to poor growth, poor brain function, decreased potential for cognitive ability, poor social interaction, decreased immune capacity with increased risk of infections, and decreased ability to heal.[241]

Suboptimal nutrition can lead to nutritional deficiencies in children with cerebral palsy, including iron, vitamin D, phosphorus, and calcium.[242] Medications that are commonly used by patients with CP have been associated with decreased feeding and nutrition because of their unpleasant taste, suppression of appetite, sedation, reduced gastrointestinal tract motility, and alterations of vitamin metabolism. Examples include anticonvulsants, muscle relaxants, pain medications, and psychiatric medications.[243]

Because of the complexity, significance, and prevalence of gastrointestinal issues in children with CP, the PCP and family may consider building a multidisciplinary team, including a nutritionist, pediatric gastroenterologist, pediatric otolaryngologist, speech and feeding pathologist, and occupational therapist to assist with optimizing care.[241,244]

Growth and Nutrition Assessments

Assessing growth and nutritional status in children with CP is difficult. Weight may be difficult to measure if the patient is unable to transfer onto a scale. In these cases, the patient may be held by a parent or weighed in a wheelchair, with the weight of the parent or chair subtracted. The parent or chair can be reweighed at each visit to improve accuracy. It may be impossible to accurately measure height in patients with scoliosis and contractures.[242] Alternative measures using knee height, arm span, or tibial and ulnar length have been developed to determine an equivalent height for patients with severe CP.[242,245,246] Some experts recommend measurement of body composition by skin fold measures, bioelectric impedance analysis, or dual energy x-ray absorptiometry (DXA) as useful in determining fat versus lean body mass[242,244] and nutritional status, but these measures may not be easily available or practical in the PCP's office. An emerging tool for evaluating growth is the mid-arm circumference, which can be used in conjunction with other measures and has been studied in youth with CP.[247,248]

As with all children, monitoring growth parameters over time using growth curves is important. Growth charts for children with CP stratified by GMFCS level have been constructed[249] using observational data from a large cohort of children from California. The authors showed a

striking association between lower weight percentile on these growth charts and risk of mortality. Some clinicians use these growth charts as part of their clinical practice, whereas others recommend using standardized growth curves with other nutritional measures, including skin fold thickness and bioelectric impedance analysis.[244,250]

Nutritional diaries of intake and examination of weight gain and other previously discussed parameters can be evaluated every 6 months to promote optimal growth and development.[242] Determining optimal caloric intake is dependent on many factors, including mobility, type of CP, and nutritional status. For example, patients who use wheelchairs may have caloric needs that are 60% to 70% less than those of ambulatory patients.[240,242] Patients who have hypertonia or athetosis may need more calories than those who are hypotonic.[251] Collaboration with a pediatric dietitian experienced in the care of children with disabilities can be helpful.

The pediatrician may consider obtaining annual laboratory tests to include iron, vitamin D, phosphorus, and calcium and supplementing daily vitamin D for those at high risk for fractures.[242,244] Guidelines for calcium and vitamin D intake for typical children have been published by the AAP[252] and are discussed in the Bone Heath section.

Feeding Methods and Diet

The patient's diet and method of feeding are individually determined by a variety of factors and involve shared decision making between the medical providers, the patient, and the parent or guardian. Oral feeding is the goal for most patients and their families, and depending on the patient's oral and swallowing skills, the texture of food and fluids may need to be adjusted so the child can swallow safely.[4,243] Other therapies to be considered include positioning adjustments and oromotor training to prevent aspiration and/or improve swallowing.[87,243] Combined electrical stimulation with oral sensorimotor treatments is an emerging therapy that may improve swallowing and has been recommended by Novak et al in their systematic review of therapies for CP.[87,253] Consultation and ongoing therapies from speech and feeding therapists and occupational and physical therapists are useful in assessing and treating oral feeding problems.

When a child cannot take oral feeding safely, nonoral feeding may be considered. Approximately 1 in 15 patients with CP have a feeding tube.[137] The benefits of tube feeding for these patients include improved nutritional status and weight gain, decreased length of time to feed the child, and improved experience of feeding for the child and family.[243] Options for nonoral feeding include nasogastric tube feeds (usually reserved for feeding issues expected to be temporary) or a gastrostomy tube (G-tube) or gastrojejunostomy tube (G-J tube) when the need for enteral supplementation is expected to be long-term.[243] Depending on the clinical situation, nonoral feeding can be used in combination with oral feeding, such as when a child eats by mouth during the day but receives supplemental nutrition during the night.[254] The decision to consider nonoral feeding is often difficult for the family, and a shared decision-making approach can be used.[76] A full discussion of shared decision making for nonoral feeding is available from a recent AAP report.[76]

Gastrostomy tubes can be placed percutaneously, endoscopically, or surgically. Gastrojejunostomy tubes are typically placed using fluoroscopy through an existing gastrostomy. Gastrojejunostomy feedings can be considered when there is ongoing severe vomiting, aspiration, or symptomatic gastroesophageal reflux in a patient who has a gastrostomy.[243] Reviews of surgical interventions show that G-tubes and G-J tubes lead to increased weight gain.[239,255,256] Perioperative risks are rare but include hemorrhage, infection, and bowel perforation.[257] In the longer-term, there is a risk for overfeeding, increased storage of fat, and worsening of symptomatic gastroesophageal reflux,[239] which may have untoward effects on the child's overall health. Especially concerning in severely affected patients is the balance between weight gain and the family's ability to lift, carry, or transfer their child.

Drooling

Drooling is seen in approximately one-third of children with CP. Causes include difficulty with coordination of the oromotor system, dysphagia, GERD, and side effects from medications, such as certain anticonvulsants and neuroleptics.[254,258,259] Drooling becomes problematic when it causes skin irritation, wet clothing, and odor and, if associated with difficulty swallowing, may cause aspiration. Children and families may also find drooling stigmatizing.[254] Improving positioning, oromotor therapies, and behavioral therapies can be used to treat drooling for children with CP. Behavioral strategies and oromotor therapies are most effective in those with higher cognitive levels or less profuse drooling.[259] When symptoms are excessive, salivation can be reduced by medications (anticholinergic medications such as glycopyrrolate), botulinum toxin injections to the salivary glands, and in severe cases, salivary gland surgery.[213,254] An evidence-informed care pathway is available from the AACPDM to assist with decision

making around drooling therapies.[260] This guideline is periodically updated and available at https://www.aacpdm.org/publications/care-pathways/sialorrhea-in-cerebral-palsy.

Gastroesophageal Reflux Disease

A distinction is made between gastroesophageal reflux, the asymptomatic admission of gastric contents to the esophagus, and when symptoms are caused by food contents and acid in the esophagus, gastroesophageal reflux disease (GERD).[261] The prevalence of GERD in children with CP is not clear; however, children with significant neurologic problems have a prevalence of 60% to 90%.[262] In addition to causing problems with feeding, GERD can lead to aspiration of gastric contents and acid, potentially leading to pneumonia, bronchospasm, esophageal ulcers, strictures, and Barrett's esophagus.[254] Symptoms of GERD may be difficult to discern in a nonverbal child. Symptoms can include vomiting, increased salivation, food refusal, irritability, pain, anemia, hematemesis, cough, and recurrent pneumonias.[242,254] Formal evaluation for GERD can include invasive testing, such as endoscopy or combined pH and impedance testing; however, because GERD is common in children with CP, an empirical trial of acid reduction with a histamine-2 blocker or a proton pump inhibitor (PPI) can be appropriate.[244] Treatment can also include thickening of feeds, avoiding acid-producing foods,[243] or trialing different formulas, including elemental ones, which may diminish reflux by accelerating gastric emptying.[244,254] Prokinetic agents to improve gastrointestinal tract motility, such as metoclopramide and cisapride, are not commonly used because of adverse effects and lack of effectiveness; however, erythromycin is often used for this purpose.[244,263] Caution is recommended with long-term use of proton pump inhibitors because of concern about increased risk of infections as well as decreased bone mass and increased risk of fractures.[264,265] Cyproheptadine may be used to improve gastric accommodation, which can reduce reflux.[266]

When reflux cannot be treated medically, a fundoplication or postpyloric feeding can be considered,[267] although recent guidelines from the European Society of Pediatric Gastroenterology, Hepatology and Nutrition only recommend fundoplication in children with severe gastroesophageal reflux that cannot be managed medically.[244] A disadvantage of jejunal feeding is that it must be delivered by slow continuous infusion and the patient must be fed for many hours of the day. If available, consultation with a pediatric gastroenterologist, feeding team, or pediatric surgeon is recommended to review the risks and benefits of these procedures so that informed decision making can occur on the part of the patient and family.

Constipation

Constipation occurs in up to 75% of children with CP.[254] Risk factors include limited mobility or ambulation, low-fiber and low-fluid diets, low tone, and decreased gastrointestinal tract motility.[254] Diagnosis and treatment is similar to that in typical children and may include stool softeners, laxatives, suppositories, and enemas.[244,254] History, physical examination, and when indicated, a rectal examination are recommended to make the diagnosis. Symptoms associated with untreated constipation can include abdominal pain, vomiting, decreased food intake, recurrent urinary tract infections, and encopresis.[254] Initial therapy includes dietary changes including increasing fiber and fluids, with the addition of osmotic laxatives (such as polyethylene glycol or lactulose).[244,254,268] Other medication options that can be used or added include stimulant laxatives, such as senna and bisacodyl and milk of magnesia.[268] Caution should be used with all oral medications in those children with high risk for aspiration. In particular, aspiration of mineral oil may cause a dangerous lipoid pneumonitis.[244] If symptoms are consistent with fecal impaction, the short-term use of enemas and/or high-dose osmotic laxative are recommended.[244,268] There is some evidence that children with neurologic impairment do not respond as well to laxatives as typically developing children.[244] Intermittent or routine use of enemas or suppositories is used by some when oral laxatives are not well tolerated or are ineffective.

URINARY PROBLEMS

Urinary incontinence is common in individuals with CP, affecting approximately 25% to 40%.[269–271] Children with CP who are continent tend to achieve this at a later age than typically developing peers.[269,270] In 1 study, the median age for achieving daytime continence in children with CP was 5.4 years compared with 2.4 years in controls.[269] Multiple factors can contribute to difficulties attaining continence, including physical impairments affecting the ability to get to the toilet and manage undressing and hygiene, cognitive delays, difficulty communicating the need to void, and voiding dysfunction.[270,271,272] Accessible restrooms, adaptive toileting equipment, and the availability of caregivers or aides to assist with toileting are key to achieving continence for some youth with CP. Accessibility of restrooms in the

community is a concern, particularly for adults with CP.[272]

Although the degree of motor and cognitive impairments tend to be the most significant factors affecting continence,[269,271] some individuals with CP can have voiding dysfunction or neurogenic bladder.[271,273,274] In addition to incontinence, other symptoms can include urinary urgency, frequency, leakage, urinary retention, hesitancy, and recurrent infections.[271,272,275] Voiding dysfunction occurs across GMFCS levels but is more common at higher levels.[271,272,276]

Upper urinary tract deterioration appears to be relatively uncommon in this population,[271,274,275] but adults with CP do have an increased incidence of chronic kidney disease, and lower urinary tract problems are an associated risk factor.[277] Urinary retention, symptoms of detrusor-sphincter dyssynergy (eg, hesitancy, interrupted voiding) and febrile urinary tract infections can be indicators of upper urinary tract deterioration or anomalies.[275,276]

Within the medical home, pediatricians can ask patients and caregivers about incontinence and other urinary symptoms. They can provide prescriptions for adaptive equipment, such as grab bars for toilet transfers or raised toilet seats when needed to facilitate toileting or increase independence. Evaluation by an occupational therapist may be helpful to determine what type of equipment is most appropriate. Some insurance companies will cover incontinence supplies for incontinence attributable to severe motor disability or cognitive impairment. Conservative interventions such as adequate fluid intake, timed voiding, avoiding caffeine, and addressing constipation are effective for many patients with a voiding dysfunction.[271] Referral to urology for further evaluation, such as urodynamic studies, can be considered for patients with persistent urinary symptoms despite conservative management or when there are concerns upper urinary tract abnormalities. Some patients with urgency or urine leakage attributable to bladder detrusor overactivity may benefit from anticholinergic therapy, although this requires caution because of the potential for urinary retention and worsening constipation.[271,273] Clean intermittent catheterization may be indicated for patients with urinary retention or detrusor-sphincter dyssynergy.[273,276]

BONE HEALTH IN CEREBRAL PALSY

Patients with CP are at risk for poor bone health and fragility fractures. Estimates of fracture prevalence range from 6% to 12% of patients.[278,279] In addition to the pain associated with fractures, children with CP are likely at higher risk for fracture malunion, surgical complication, and permanent loss of function.[280] It is unclear whether children with CP are at higher risk for fracture-associated venous thromboembolism,[281] but this can be considered as well because of the risk of serious morbidity and mortality.

As the majority of lifetime bone accrual occurs during childhood, it is critical that bone health be maximized for children with CP.[282,283] The causes of low bone mass in this population are multifactorial. Probably the most important risk factor for low bone mass with subsequent fracture is inability to bear weight, and there is a clear relationship between ambulatory ability and risk of fracture.[284,285] Other risk factors include prematurity,[286] poor nutrition,[287] and chronic illness.[288] Many medications that interfere with bone metabolism are commonly used by patients with CP, including certain antiseizure drugs,[289] loop diuretics,[290] corticosteroids,[291] acid-reducing medications,[292] and medroxyprogesterone acetate.[293] Children with CP are also at increased risk for fracture from falls[294] or inflicted trauma.[71]

The AACPDM has published a Care Pathway for the assessment and treatment of low bone mass in children with CP[295] (Fig 4). This evidence-based guideline is periodically updated and available at https://www.aacpdm.org/publications/care-pathways/osteoporosis-in-cerebral-palsy.

Assessment of Bone Health

The first step in bone health assessment is to examine the child's nutrition for an adequate intake of calcium and vitamin D.[296] Optimal calcium intake varies by age. The major source of vitamin D for the body is synthesis in the skin from exposure to UV radiation, so vitamin D deficiency is highly prevalent among people who live in higher latitudes, have darker skin, or have limited outdoor sun exposure. Many experts suggest monitoring levels of calcifediol (25-OH-D) in the blood, as this is the storage form of the vitamin. The optimal blood level is controversial, but 20 or 30 ng/mL is often used as a threshold. Vitamin D may be supplemented empirically with 800 to 1000 U of cholecalciferol (vitamin D_3). This formulation is usually preferred to ergocalciferol (vitamin D_2), because it may be more effective at increasing the 25-OH-D level in the blood.[297]

In the absence of a history of a fracture, it is controversial whether to assess bone mass using DXA. The utility of this (or

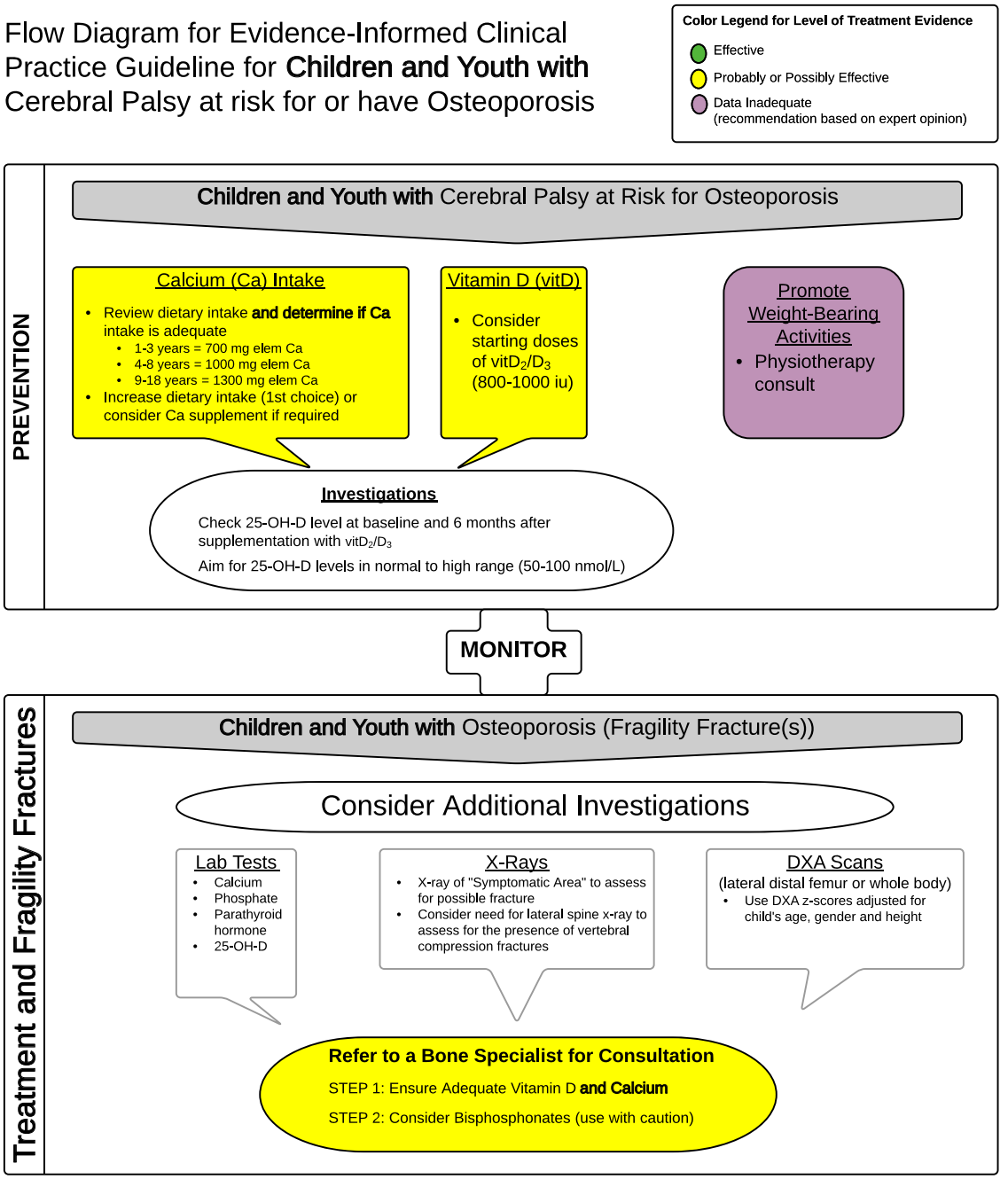

FIGURE 4

AACPDM bone care pathway. Reproduced with permission from: Fehlings D, Switzer L, Stevenson R, Gaebler-Spira D, Dalziel B, Ozel S. AACPDM Osteoporosis Care Pathways. American Academy of Cerebral Palsy and Developmental Medicine. Published September 2016. Accessed 19 Aug 20 from https://www.aacpdm.org/publications/care-pathways/osteoporosis-in-cerebral-palsy.[431] Note: AACPDM Care Pathways are clinical practice guidelines for the health care of individuals with childhood-onset disabilities. Their main goal is to develop recommendations that allow users to understand the evidence on a topic and apply it to clinical practice. The Osteoporosis Care Pathway was developed from the best available evidence at the time of its development, and the information contained could change or be updated with emerging or new evidence. Please be sure to visit the website https://www.aacpdm.org/publications/care-pathways/osteoporosis-in-cerebral-palsy for updates.

other tools such as quantitative computerized tomography or ultrasonography) as a screening tool has not been established.[298] Available guidelines[295,299] do not support treating low bone mass (on the basis of a DXA scan alone) without fracture with a bisphosphonate.

When a patient has had a fracture, DXA is the most commonly used modality to assess bone mass. This modality is noninvasive and involves a relatively low dose of radiation.[298] A raw bone mineral density score is measured at 1 or more body sites, which is then compared with a database of healthy children matched for age, sex, and self-reported race and ethnicity. This produces a *z* score in which a *z* score of 0 represents the median bone density at that site, and the normal range is considered to be 2 standard deviations above or below this, between a *z* score of +2 and −2. In children, the *z* scores are further adjusted by height to account for different sized bones in smaller children.

The acquisition and interpretation of these scans in children, particularly those with disabilities, requires specialized expertise.[300] Height-adjusted *z* scores can be used if available. Because of orthopedic deformities, children with CP may have trouble laying comfortably on the scanning table in the proper position. Contractures, scoliosis, and implanted hardware may interfere with interpretation, as the analyzed sites are typically the lumbar spine and total body. In lieu of these sites, the lateral distal femur has been developed as an alternate region of interest, with its own normative database.[301] This region of interest is more easily obtained in children with scoliosis or contractures, and there is rarely surgical hardware present to interfere with the reading. These distal femur *z* scores correlate well with fracture history among children with CP.[302]

When a patient has more than 1 region of interest studied, the lowest *z* score is used. If the *z* score is less than −2.0, low bone mass for age is present. If this is accompanied by a history of fragility fracture, osteoporosis may be diagnosed.

A metabolic evaluation is useful to rule out other causes of reduced bone mass. In addition to vitamin D, patients are usually screened for perturbations in calcium and phosphorous metabolism, hyperparathyroidism, hyperthyroidism, liver and kidney dysfunction, celiac disease, and hypercalciuria.[295] If any of these are found, treatment of the underlying disorder can be initiated.

Treatment of Osteoporosis

As described earlier, every child with osteoporosis benefits from a nutritional assessment, with particular emphasis on adequate intake and absorption of calcium and vitamin D. Excessive intake of sodium, calcium, and vitamin D ought to be avoided, because these can increase the risk of kidney stones.

As limited weight-bearing exercise is believed to be the major cause of low bone mass among children with CP, there has been interest in measures to improve weight bearing as prevention or treatment of osteoporosis. However, the studies of these interventions have been small, and it is unclear how much weight bearing is needed to improve bone density and reduce fracture risk.[303,304] Because engaging in functional weight-bearing activities, the use of standing frames, supported walking on a treadmill, or exercise bicycles are safe and possibly effective, these are recommended as tolerated by the patient.

Pediatric bone experts may be consulted for the treatment of osteoporosis in children. Intravenous bisphosphonates, such as pamidronate and zoledronic acid, are the most commonly used medications to improve bone density.[299,305–307] Oral bisphosphonates are less commonly used because of the potential to cause erosive esophagitis, although this has not been reported in small studies of children with disabilities.[308,309] The mechanism of action of this class of medications is to inhibit the action of osteoclasts, reducing bone turnover. These are generally well tolerated,[310] although more than 75% of patients will have an acute-phase reaction consisting of fevers, myalgias, and fatigue, which usually subsides after a few days. This is generally worst with the first infusion.[311] There may be transient hypocalcemia as bone uptake of calcium is increased. Severe complications of bisphosphonate use, such as osteonecrosis of the jaw and atypical fractures of the femur, are extremely rare in children.[299] The risk of these can be mitigated by maintaining good dental health, avoiding invasive dental procedures while on therapy, and limiting the duration of bisphosphonate therapy.[312,313] It is important to note that although bisphosphonates have been shown to increase bone density in children with CP,[305] only a few studies have shown a reduction in fracture incidence, likely because of small sample sizes.[306,310,314]

STRENGTHENING AND TONE MANAGEMENT

Children with CP have motor disability that may be attributable to weakness, abnormal tone, or both. These conditions are attributable to the cerebral pathology or injury; hypertonia is considered a “positive” feature of the upper motor neuron syndrome, and weakness is a “negative” feature.[315] These abnormalities, which often change over time, are the prime example of how this “nonprogressive” disorder can evolve. The PCP’s role is to identify patients who would benefit from tone management by a specialist. Depending on community resources, tone might be managed

by a pediatric physiatrist, pediatric neurologist, or developmental pediatrician.

Children with less motor ability (higher GMFCS level) tend to be weaker, and weakness, rather than spasticity, is the major determinant of motor ability.[316,317] Weakness in CP is both a primary and a secondary problem. The muscles of children with CP are smaller and shorter and produce less force than those of typical children. This decreased muscle mass, combined with tone and orthopedic abnormalities, leads to more sedentary behavior for children with CP, further exacerbating weakness. Physical and occupational therapy and resistance training is safe and improves strength in children with CP and may be encouraged throughout the lifespan.[100,318,319] In addition to building strength, exercise programs for children with CP can include cardiorespiratory exercise and can be developed with the assistance of physical therapists, recreation therapists, and knowledgeable physical educators or athletic trainers.[320] The first step in tone management is to determine the nature of the tone or movement abnormality (Table 1). *Spasticity* is a velocity-dependent resistance of a muscle to stretch, in which the muscle tightens more when the muscle is moved more quickly. There is often a "clasp-knife" response, in which sustained stretch of the muscle beyond a certain point results in relaxation. *Dystonia* is both a tone disorder and a movement disorder; it is characterized by involuntary sustained or intermittent muscle contractions which cause twisting and repetitive movements, abnormal postures, or both.[15] Other movement disorders seen in children with CP include random involuntary movements (*chorea*), continuous involuntary writhing movements (*athetosis*), and poor balance and coordination (*ataxia*), although these are less common.[321] Many patients have spasticity of the limbs while there is hypotonia of the trunk, but some patients remain hypotonic throughout their bodies for their lifetime. It is believed that these patients are more likely to have an underlying genetic or metabolic etiology, and further evaluation may be warranted.[38]

The management of spasticity is usually multimodal. It is important to keep in mind that tone reduction alone is not the end goal. For an individual patient and family, the goal could be improvement in function, reduction of pain, maintenance of joint architecture, improved hygiene, or others. In some cases when spasticity is reduced, it becomes evident that the patient is also very weak and that spasticity was allowing the patient to perform certain functions, such as standing.[315] In addition, removal of spasticity can allow dystonia to emerge, particularly after selective dorsal rhizotomy.[322] Careful assessment of strength, tone, and goals is imperative before treatment can be chosen.

Physical and occupational therapies are part of most treatment programs, as spasticity reduction is augmented by strengthening and training in new motor skills. Most patients are prescribed passive stretching exercises to reduce tone and maintain range of motion. Evidence that stretching alone improves spasticity is limited, and sustained stretching using a brace or serial casting is probably more effective.[323] Bracing and proper positioning can improve function even if the strength or tone is not improved.

The best-studied pharmacologic treatment of spasticity is injection of botulinum toxins A or B directly into spastic muscles, which blocks transmission of acetylcholine at the neuromuscular junction.[86,179] This can often be accomplished in the office without sedation. These injections are most commonly used when there is localized or segmental spasticity and are often combined with bracing and casting. This treatment is generally regarded as safe. Side effects include pain at the injection site or excessive weakness of that muscle, but these are temporary. Rarely, there can be systemic effects, such as dysphagia, dysphonia, or dyspnea.[324] Alternatively, other neurotoxins, such as phenol or alcohol, can be injected into the spastic muscles at the motor points or perineurally, which cause chemical denervation, although evidence of safety and efficacy in CP is limited.[179]

Oral medications are commonly used for generalized spasticity, although dosing is often limited by sedation, which is a common side effect of all such medicines. Most widely used is baclofen, a γ-aminobutyric acid agonist that binds to receptors in the spinal cord. Baclofen may be associated with increased seizures in patients with epilepsy, although this is not a contraindication to treatment.[325] Benzodiazepines, such as diazepam and clonazepam, are γ-aminobutyric acid agonists in both the spinal cord and brain. Long-term use of benzodiazepines may be limited by the frequency of side effects and development of tolerance.[315]

To combat the dose-limiting sedation of oral medications used to treat spasticity, baclofen may be delivered by an intrathecal pump. This pump allows much smaller doses of the medication to be delivered to the site of action in the spinal cord with less systemic effect. The baclofen pump is most commonly used in children with CP who cannot ambulate, level IV or V

on the GMFCS.[326] The pump is usually placed beneath the abdominal skin or fascia and delivers baclofen by a catheter that is tunneled from the pump to the spinal canal to deliver the medication directly into the intrathecal space. The pump can be programmed to deliver a continuous infusion of baclofen or a complex dosing regimen depending on the desired effect. The pump reservoir is refilled every few months by injection through the abdominal skin; failure to do so can result in baclofen withdrawal. Complications, which are reported to be as high as 10% to 15%, include kinking or dislodgement of the catheter, leakage of cerebrospinal fluid, or failure or infection of the pump.[327, 328] If any of these cause the flow of baclofen to be interrupted, a withdrawal state may emerge, characterized by pruritus, fever, altered mental status, and increase in spasticity. If withdrawal is suspected, oral baclofen or a benzodiazepine can be given and the patient and pump emergently evaluated.[329] If not recognized, baclofen withdrawal can lead to death.

Selective dorsal rhizotomy (SDR) is a neurosurgical procedure that permanently interrupts the reflex arc that causes spasticity in the legs. With intraoperative neurophysiologic monitoring, a portion of the afferent sensory rootlets in the lumbar spine is identified and transected while sparing the motor rootlets.[330] Traditionally, SDR was reserved for ambulatory children whose spasticity was limiting motor gains. More recently, nonambulant children with spasticity causing pain and/or joint abnormalities have received SDRs in an effort to improve pain and ease of caregiving.[326] Complications and side effects of SDR are less frequent than intrathecal pump implantation and are usually temporary; these include dural leak, meningitis, paresthesias, and urinary retention. Because SDR only improves spasticity, its removal may allow an underlying dystonia or weakness to become prominent.[322] Postoperative rehabilitation is needed for strengthening and to achieve the best postoperative outcome from SDR.[331]

When tone abnormality causes reduced range of motion around a joint, the muscle can be shortened, and contracture can occur. This contracture can be treated by stretching and serial casting, but tendon lengthening procedures are often needed to restore the range of motion. These procedures improve tone and range of motion in the short term, but if the underlying spasticity is not relieved and range of motion maintained, contracture is likely to recur.[317]

Treatment of dystonia is difficult even for experts and evidence is limited; referral to a movement disorder specialist may be beneficial. A recent systematic review endorsed intrathecal baclofen or deep brain stimulation as "possibly effective."[87] Other commonly used but inadequately studied treatments include oral baclofen, levodopa, trihexyphenidyl, botulinum toxin injections, benzodiazepines, clonidine, and gabapentin.[332]

Tone may increase transiently during acute illness or because of pain from any cause. This change in tone often alerts the family and physicians to look for noxious stimuli, such as infection, fracture, constipation, etc.

ORTHOPEDIC CONSIDERATIONS

Musculoskeletal problems are major secondary morbidities for patients with CP. These problems may cause pain, decreased function, difficulty with care, pressure ulcers, and cardiopulmonary problems. For growing children with CP, abnormal tone causes stresses on the bones and joints, which can cause them to develop incorrectly. The risk of developing incorrectly may be decreased through tone management, stretching, bracing, and proper wheelchair seating. Maintenance of joint position and strengthening of the upper extremities can help the child develop self-care skills needed for independent functioning in dressing, eating, etc.

Although any joint may be affected by these abnormal stresses, orthopedic care of the spine and hips are of major importance. Surgical correction is often performed for these children, despite higher perioperative morbidity and risks of complications. The PCP's role is to identify when referral to orthopedics is necessary, facilitate regular follow-up, and optimize the child's medical health before and after surgery.

Hips

Normal development of the hip structures, including the shape of the femoral head and placement in the acetabulum, is dependent on normal weight bearing and muscle tone, so children who cannot stand or have abnormal tone have a high likelihood of abnormal hip development.[333] Hip abnormalities can be associated with pain, hygiene problems, and reduced mobility, participation, and quality of life.[334]

Active surveillance of the hips of children with CP reduces the rate of hip subluxation and dislocation by early detection of hip dysplasia and appropriate referral for orthopedic treatment. Several surveillance programs have been proposed[335,336] that use elements of the clinical examination and hip radiographs (standard anteroposterior view of the pelvis). As the likelihood of hip dislocation increases with age and GMFCS level, recommendations are tailored for each patient depending

on functional ability. The AACPDM has published a Care Pathway for the assessment and treatment of hip displacement in children with CP. This evidence-based guideline is periodically updated and available at https://www.aacpdm.org/publications/care-pathways/hip-surveillance-in-cerebral-palsy (Fig 5).

On hip examination, the range of motion is noted, along with the presence or absence of spasticity and pain with passive or active movement. The "migration percentage" of each hip is calculated using the pelvic radiograph (Fig 6). Orthopedic referral can be made when there is pain in the hip, reduced hip abduction, or migration percentage >30%, as this dramatically increases the risk of hip dislocation.[337]

When hip subluxation is mild, reducing spasticity with oral medications or injection of botulinum or other neurotoxins may be helpful, although high-quality evidence is lacking.[338] If this protocol is unsuccessful, the child may be a candidate for a "preventive" hip surgery, in which muscles are released or lengthened to reduce the abnormal stress on the bones and modify the abnormal growth of the femoral head and acetabulum. If hip subluxation progresses, "reconstructive" surgeries are needed. These involve osteotomies of the femur or pelvis. If the hip is painful and dislocated, a "salvage" procedure, such as hip replacement or femoral head resection, may be indicated to reduce pain and improve seating.[339]

Hip reconstruction (osteotomy) is the most common procedure performed and has been shown to improve quality of life in these children.[340] Complications after hip surgery are common, with reported

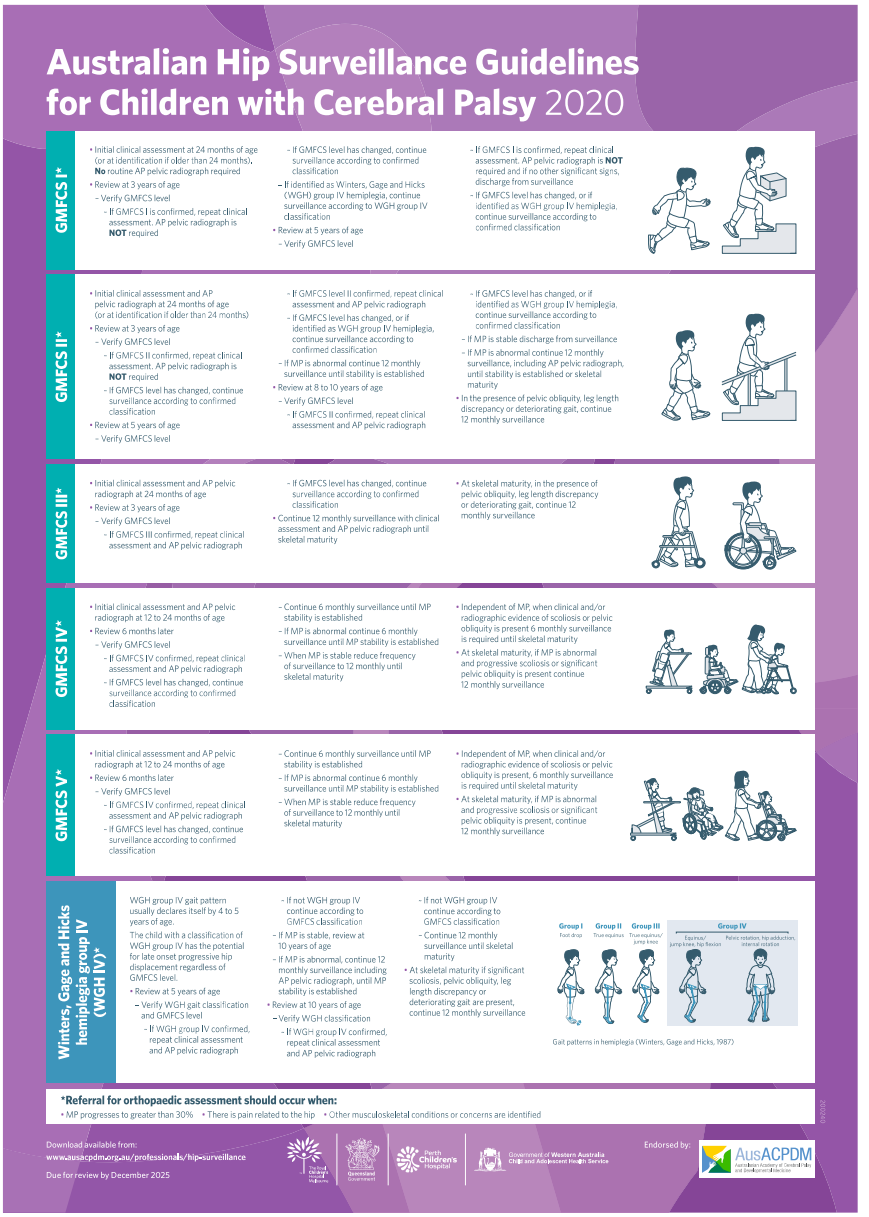

FIGURE 5
Australian hip surveillance guidelines for children with cerebral palsy 2020. Reproduced with permission from: The Australasian Academy of Cerebral Palsy and Developmental Medicine. Australian Hip Surveillance Guidelines. AusACPDM.org.au.https://www.ausacpdm.org.au/resources/australian-hip-surveillance-guidelines/.

rates between 21% and 65%,[341–344] although most of these are minor and related to skin issues. The outcome of hip reconstruction is moderately successful, with better success rates in patients who are more ambulatory, older, have less severe dysplasia, or have more experienced surgical teams.[345]

Spine and Scoliosis

Abnormal muscle forces and asymmetric stresses on the spine cause scoliosis in patients with CP. The spine deformities result from truncal weakness, spasticity, and hip abnormalities in which the patient sits on an unstable base. Scoliosis is much more likely to occur in patients with less ambulatory

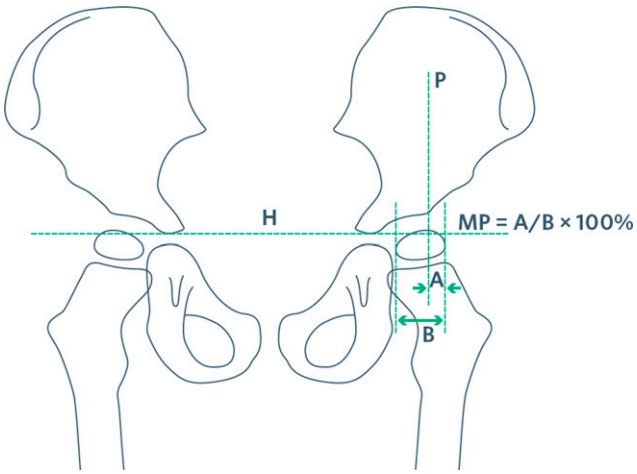

FIGURE 6
Measuring hip migration. Reproduced with permission from: Wynter M, Kentish M, Love SC, et al. Australian Hip Surveillance Guidelines for Children with Cerebral Palsy. 2014.

ability; in one recent population level study, 55% of patients functioning at GMFCS level V developed scoliosis, but no patients classified as GMFCS level I developed scoliosis.[346]

When the patient is younger and the degree of scoliosis is smaller, scoliosis can be managed with conservative measures, such as tone management, bracing, improved seating, attention to hip asymmetry, and trunk strengthening. A common brace used for scoliosis is a thoracolumbosacral orthosis. There are several styles of these, with differing amounts of rigidity. Patient tolerance of these varies, as they may be uncomfortable or restrict breathing. The thoracolumbosacral orthosis brace has been shown to improve seating position and participation in daily activities but not to prevent progression of the curve in patients with CP.[347] With their limited effectiveness in preventing curve progression, they are prescribed primarily for positioning support.

Spinal surgery, primarily spinal fusion, may be suggested when the curve progresses, but the specific decision to proceed with surgery is individualized and depends on patient factors and family goals. Commonly stated and evidenced-based indications include stopping the progression of the curve, improving posture and seating, and making care easier.[348] Families often also hope that improvements in spinal alignment will improve function and reduce back pain and respiratory comorbidity, but the evidence for these is equivocal.[349] There is strong evidence that the care of these children is easier, and the children's quality of life improves after spine fusion.[350]

Surgical techniques vary dependent on age of the patient, degree and location of the spinal deformity, and surgeon preference.[351] If possible, it is generally preferred to postpone spinal fusion until after thoracic growth is complete, usually around 10 years of age. If earlier correction is needed, "growing rods" can be placed. These are adjustable and can be lengthened over the child's remaining growth period.[352] Newer rods can be "grown" magnetically, making this a desirable alternative as it obviates the need for anesthesia and surgery every 6 months as the child grows. However, these growing rod constructs have a higher complication rate and are only used in extreme circumstances when the child is very young.

Complications are common after spinal surgery. A recent meta-analysis found a mean complication rate of 38%.[349] These include perioperative bleeding, postoperative respiratory compromise, wound infection, hardware displacement, and pancreatitis. Perioperative death has been reported in less than 1% of patients.[353] Initial postoperative care is usually provided in the pediatric ICU.

Because of the uncertain benefit of scoliosis surgery and likelihood of complications, some authors have urged caution in the routine performance of spinal fusion.[217] However, the family can be advised that if surgery is not performed, the scoliosis is likely to progress with worsening positioning, increased pain, increased risk of pressure injuries, and possible progression of restrictive lung disease. This particular surgical decision is often used as a prime example of shared decision making between the surgeon, family, primary care provider, and specialists who will work as a team to care for the patient before and after surgery. Early involvement of palliative care specialists in this discussion can be helpful. Some centers have created comanagement teams to decrease complications and improve outcomes after spinal surgery.[354] If the family makes the decision not to proceed with surgery, the palliative care specialists can work with the PCP and other physicians to maximize comfort and quality of life.

PRESSURE INJURIES

A subgroup of children and adolescents with CP are at high risk for pressure injuries. Although the

specific incidence is not available for children with CP, the prevalence of pressure injuries in all children range from 1.4% to 8.2%, with much higher rates found in hospitalized children.[355] Any child who has decreased mobility, difficulty moving himself or herself to another position, inadequate nutrition, intellectual developmental disorder, decreased sensation, or a history of a pressure ulcer is at higher risk for a pressure injury.[356] Pressure injuries and ulcers commonly occur in bony areas that are "prominent" (back of the head, sacrum, heels, etc) and in and around areas with medical devices that lay on the skin (feeding tubes, tracheostomies, respiratory masks, etc).[355] Pressure injury can lead to damage to tissues, ulcers, infection, and pain and can be prevented.[357] Prevention strategies include frequent repositioning ("more frequently than every 4 hours"), padding, wheelchair cushions, and special mattresses to protect bony and dependent areas. Correct fit of medical devices is important. These may need to be replaced or refitted periodically.[86,355]

If a pressure ulcer occurs, a standardized scale can be used to evaluate the stage of the ulcer in addition to describing the ulcer size, depth, and location.[355] Treatment depends on the stage of the injury or ulcer and may include moist dressings, chemical or mechanical debridement, antibiotics, and use of "pressure-redistributing devices," such as specialized mattresses or pads. In all cases, pressure on the area ought to be minimized and nutrition optimized. Pressure injury prevention, early diagnosis, and treatment are recommended to prevent complications.[355] Pressure injuries may need a multidisciplinary team to prevent and treat, including orthopedics, plastic surgery, dermatology, gastroenterology, pediatric physiatry, nutrition, specialized wound nurses, occupational therapists, and physical therapists.

PAIN

Pain is a significant problem in children and youth with CP but is not always recognized or addressed by the doctors taking care of them.[358] Studies show that the frequency of pain in children with CP varies but can be present in as many as 75% of patients.[137] Pain has been reported in patients of all GMFCS levels; however, those with less motor function have the greatest rates of pain.[358–360] Other risk factors for pain in patients with CP appear to be female sex, "general ill health," and increasing age.[358,361] Chronic pain has been reported to decrease quality of life, decrease participation in school and social events, cause mood problems, and increase anxiety in individuals with CP.[358,360,361] Because of the high frequency and impairment to functioning and family life, it is helpful to discuss pain with the patient and parent or guardian, not only after a surgery or when raised by patient or family, but at every routine health care maintenance visit.[169,362]

The source of pain in patients with CP is most commonly musculoskeletal and is attributable to spasticity, dystonia, and contractures, predominantly in the hips, knees, and feet. Other common sources of pain in patients with CP include gastrointestinal causes (GERD, constipation, gallstones, abdominal pain, and dysmotility), kidney stones, headaches, dental problems, occult fractures, and other sources.[242,360–363] Hip pain attributable to subluxation has been highlighted as a common source of pain that can be prevented if close monitoring and early surgical intervention occurs.[361,364] In 1 study, pain was reported to be most severe for ambulatory patients during voluntary movements, whereas those with less ambulatory ability had more severe pain when they were being moved.[361]

To properly assess pain, consider whether the pain is acute, chronic, recurrent, or constant.[169] If pain is acute, the source can often be identified and treated. Pain that is chronic or recurrent can be attributable to the somatic problems described earlier but can also be caused by abnormalities of pain processing in an impaired central nervous system. This "centrally mediated pain" is poorly understood and may be called "central neuropathic pain," "visceral hyperalgesia," or "dysautonomia." These types of pain may be hard to identify and define.[169] When the etiology of pain cannot be identified by history, examination, or targeted medical testing, it may be attributable to central pain, and an empirical medication trial aimed at neuropathic pain may be helpful.[169]

Assessing the level of pain is an important part of evaluating and monitoring treatment. Although pain assessment tools exist, none have been validated in children with CP.[360,361] Pain assessment tools like the FACES pain scale[363] can be used in children who function at a developmental level of more than 3 years of age.[169] Pain assessment can be particularly difficult in patients with CP who are nonverbal and/or have an intellectual developmental disorder because of their inability to communicate the location and severity of their pain. A study comparing pain scales filled out by parent and youth showed that when pain level is moderate or severe, their scores tend to be in agreement.[361] Relying on parent reports and their understanding of baseline behaviors are essential in understanding pain behaviors

observed in the child, especially when location and description of the pain is not possible.[169,362]

Treatment includes: targeting the source of the pain (if known) and using a step-wise approach to pain management. Nonpharmacologic therapies (holding, swaddling, massage and positioning, guided imagery, and self-hypnosis, etc) are the initial approach to alleviate or lessen pain. If unsuccessful, pharmacologic treatment of pain can be initiated. Medication therapy does not have to be delayed while evaluating the etiology of pain.[362] Treatment may alleviate pain symptoms and prevent a protracted evaluation, particularly in patients with chronic pain. A multidisciplinary approach is often indicated for children with cerebral palsy with chronic pain and can include specialists in gastroenterology, pediatric physiatry, orthopedics, neurology, palliative care, physical therapy, occupational therapy, and behavioral health. A full description of diagnosis, etiology, and therapies for pain is beyond the scope of this report; the reader is referred to the AAP clinical report "Pain Assessment and Treatment in Children With Significant Impairment of the Central Nervous System" as well as recent reviews for further information.[169,360]

PALLIATIVE CARE

Palliative care specialists work in conjunction with the PCP and other specialists for pain and symptom management challenges that impact quality of life.[365,366] They can assist the patient and family in clarifying goals of care, especially during times of change, in a child's prior baseline condition or in informed medical decision making.[365,366] As part of a team approach, the pediatrician and palliative care specialists can assess the social, spiritual, and emotional needs of a patient and family. Although often thought of for end-of-life care only, palliative care can assist in the care of a child with CP early in diagnosis or during ongoing care, to provide an additional long-term relationship, and support for patients and families.

FAMILY SUPPORT

Because the child with CP is part of a larger family system, assessment of the family's functioning can help guide interventions and support services. This assessment may include evaluations of family stress, social capital, resources, priorities, and adjustment of parents and siblings to having a child with a disability in the family. By listening carefully to parental concerns, pediatricians can better address the family's concerns and the child's needs. Using the World Health Organization's model for the ICF, the family is the primary environmental context for children.[73,367] When the health of parents or caregivers is compromised, outcomes for their children with (or without) CP suffer.

Caring for a child with CP can affect all aspects of a parent's life, including physical and emotional health, marital and social relationships, employment, and financial status.[368] Parents of children with CP generally experience worse physical and emotional health than do parents of typically developing children.[369] For example, Tong et al reported that more than 70% of mothers of children with physical disabilities reported low back pain.[370] Basaran et al found that almost two-thirds of caregivers of children with CP had depressive symptoms, and almost three-fourths had anxiety,[371] which is significantly higher than the prevalence in parents of typically developing children.[372] Some of the factors contributing to high stress levels in parents of children with CP include financial strain, special housing and equipment needs, social isolation, and the time required for treatment regimens.[174,368,371,373] More significant motor impairment, epilepsy, and the presence of behavioral comorbidities are associated with higher parental stress, depression, and lower levels of physical health.[174,369,371,373]

Although their stress levels are often high, many parents describe their quality of life as good and note positive aspects of caring for a child with CP.[368] Protective factors include good family functioning, opportunities for respite care,[373] support from family and friends,[374] and paid work and leisure activities.[375] Peer support groups with other caregivers of children with developmental disabilities can provide benefits in reducing social isolation, improving well-being, and increasing knowledge.[376] Family-to-Family Health Information Centers are family-led organizations funded by the Health Resources and Services Administration that provide education, technical assistance, and peer support to families of children and youth with special health care needs. They are also a resource for pediatric providers caring for these children. These centers are available in each state, the District of Columbia, and a number of US territories and tribal communities.[377]

Having a brother or sister with CP affects the well-being of siblings. Siblings report lower physical and psychosocial health compared with children who do not have siblings with a developmental disability or chronic illness as well as higher rates of behavioral and emotional problems.[378–382] In 1 study, parental report of impairment in healthy siblings was significantly less than the siblings' self-reports, suggesting that parents may not be aware of the extent of the impact on healthy

siblings.[379] On the other hand, many children do adjust well, and some children report benefits from having a sibling with special needs.[380] Multiple factors, such as parental psychological distress and other family stressors, likely interact to influence the adjustment of children to having a sibling with CP.[378,381,383] Family routines, activities, and effective communication and problem solving are protective.[381] Support groups and activities targeted to siblings of children with developmental disabilities may provide social support, enhance disability-related knowledge, and improve emotional and behavioral symptoms.[378,384,385] Further research is needed to determine how to identify those siblings at greatest risk for adjustment difficulties and how to best support them. Pediatricians, who often care for multiple children in a family, are in a unique position to recognize when siblings are experiencing challenges related to their brother's or sister's disability and to provide guidance to the family.[380]

Providing family-centered care reduces stress and enhances parental well-being.[386] Fundamental aspects of family-centered care for children with CP include emphasizing child and family strengths, facilitating family choice and control, and collaborating with the child and family in setting goals as well as good communication, including both listening and information-sharing. The Roadmap Project is an effort by the American Board of Pediatrics to improve resilience and emotional well-being of children with chronic conditions, such as CP, as well as that of their families.[172] Among the resources available through this project are tools to help pediatricians discuss emotional health, resilience, and self-care with their patients and families. PCPs can support families by considering the well-being of the whole family and assisting with referrals to community resources and support groups. Some children with CP may be eligible for Supplemental Security Income depending on family income. The AAP policy statement "Supplemental Security Income for Children and Youth With Disabilities" provides guidance for pediatricians to assist families with the application process.[387] Medical homes can screen for social determinants of health, such as food or housing insecurity, to identify families in need of additional services.[388] Medical social workers play an important role in helping families navigate financial and local resources and promoting psychosocial well-being.[389] Interprofessional teamwork and cross-systems coordination among health care teams, schools, and community programs and service providers are also key to optimizing both child and family outcomes.[386]

In addition to the challenges of parenting a child with CP, family members typically provide a significant amount of hands-on nursing care and care coordination for their children, estimated to be an average of more than 2 hours per day.[390] The amount of time spent caring for a child with CP is associated with rates of parental depression.[372] Many children with CP qualify for nursing and home health aide services, which can allow parents to provide care to other children, go to school, or maintain employment outside the home. Home health services, including in-home, private duty nursing, and/or personal care aides, are mandated services for qualified children covered by Medicaid under the federal Early and Periodic Diagnostic, Screening, and Treatment benefit, although states often place such stringent criteria on these services that families have difficulty accessing them.[22,391]

Home and community-based services waivers are a mechanism for families with higher incomes to obtain access to services that are often not covered by private health insurance. These Medicaid waivers allow individuals with disabilities to receive care in their home rather than a hospital or long-term care facility. Eligibility criteria and covered services vary by state. In many areas, the availability of qualified home nursing is limited, which can delay discharge after acute hospitalization or cause loss of employment or income for the parent(s) who must remain home to provide nursing care.[392,393] The AAP has a policy statement detailing the need for this home health care and recommends systematic changes to improve home health care for children.[394]

Although care in the home setting is preferred by most families, some will choose to place their child in a congregate care setting. This type of care is usually limited to those children with significant medical and developmental needs who require 24-hour hands-on care.[395]

PUBERTY AND SEXUAL HEALTH

Sexuality is a right of all individuals, including those with physical, developmental, and intellectual disabilities.[396,397] Preparation for healthy and safe sexual relationships needs to be part of primary health care for all youth, including those with CP. Sexual health is often an area of anxiety for parents of youth with developmental and physical disabilities because of concerns of hygiene, menses, sexual intimacy, sexually transmitted infections, possible sexual abuse, and pregnancy or fatherhood.[396,398–401]

It is recommended that puberty be discussed with the patient and family early in all genders. Early discussion is helpful for patients and families to prepare for both the emotional and physical changes that are about to occur. Children with CP may be at greater risk for early- or late-onset puberty; therefore, pediatricians may consider monitoring changes in puberty in children with CP closely, as routinely done with all patients during health care maintenance visits, and refer for evaluation with an endocrinologist if indicated.[396,397]

In girls, menstruation and issues of menstrual hygiene should be discussed in advance of the first period.[399] Discussion of menstrual management includes eliciting the patient's and parent's goals, and how menses may interfere with functioning and activities of daily living.[399] Patients and families may wish to regulate menses if periods are heavy or painful or if there is a cyclical increase in seizures or behavioral symptoms. Medical management of the menstrual cycle may include estrogen or progesterone compounds, such as oral or transdermal contraceptives, injectable or implanted progesterone, or a levonorgestrel intrauterine device.[396,399] The choice of therapy is individualized and includes a balancing of the desired effects against the burdens of delivering the medication, side effects, and possible medication interactions.[396,398,399,402,403] As an example, hormonal contraceptives may alter the metabolism of certain antiseizure medications, causing loss of seizure control, and anticonvulsants may interfere with the effectiveness of the contraceptive.[399] Possible side effects of hormonal contraception include weight gain and loss of bone mass with injectable progesterone, and risk of venous thromboembolism with estrogen-containing products. In-depth information about this topic can be found in the AAP clinical report, "Menstrual Management of Children with Disabilities."[399]

Studies show that youth with physical disabilities are as likely as their nondisabled peers to be sexually active but less likely to talk to health professionals about their sexual history.[401] Youth with mild intellectual developmental disorder are also as likely to be as sexually active as their peers.[396] Two small studies of young adults (16–25 years old) with CP and typical intelligence suggested that better self-esteem and "sexual self-esteem" were more highly associated with sexual activities and romantic relationships.[404] One of these studies reported that those with higher GMFCS were less likely to have "sexual activities" but not less likely to have romantic relationships.

Youth with physical and developmental disabilities are at higher risk of sexual abuse compared with their peers without disabilities.[69,396,397] During their lifetime, this population has a 2 to 10 times higher odds of experiencing sexual abuse compared with the overall population.[396] For adolescents with CP and typical intelligence or mild intellectual developmental disorder, privacy and confidentiality during the examination is indicated. Confidentiality gives the opportunity to discuss sexuality, menstrual management, promote safety, uncover a history of unwanted sexual situations, discuss sexual preferences and gender identity, and promote appropriate protection from sexually transmitted infections and unwanted pregnancies.[398,405] State-specific legal restrictions need to be taken into consideration. Pediatricians need to be aware of behavioral symptoms that could be suggestive but not specific for abuse to investigate or refer for investigation.[402,406]

As with all adolescents, screening youth with CP for sexually transmitted infections (including gonorrhea, *Chlamydia*, HIV, and others if clinically indicated) is recommended for those who are sexually active, have symptoms, or have risk factors for sexually transmitted infections.[396] This guidance is periodically updated by the AAP and available at https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/adolescent-sexual-health/Pages/STI-Screening-Guidelines.aspx.

Sex education is essential for all youth and should not be ignored in youth with CP.[54] Pediatricians, in conjunction with parents, schools, and communities, can be sources of this education geared at an adolescent's capacity.[405] Sexual education, included as part of the IEP, includes the same topics as the curriculum of typically developing children, modified to the abilities of each child.[402] Guidance on healthy safe sexual development, protection, internet safety, and abuse prevention are essential parts of this education.[398] Vaccination against human papillomavirus is recommended for all youth, including youth with CP.[397] Prevention of sexually transmitted cancers with the human papillomavirus vaccine is particularly important because of the likelihood of sexual activity, increased rates of sexual abuse, and barriers to performing screening pelvic examinations in youth with CP.[396,407] There are recent AAP publications about adolescent sexuality, menstrual management, and sexual abuse, including the updated clinical

report, "Promoting Healthy Sexuality for Children and Adolescents With Disabilities"[397] and "Maltreatment of Children With Disabilities"[69] that provide further guidance and detailed information for the PCP.

TRANSITION AND TRANSFER OF CARE

Health Care Transition

Late adolescence and early adulthood is a vulnerable time for those with special health care needs. If proper preparation and handoff to physicians specializing in adults does not occur, there is an increased risk of morbidity, medical complications, unnecessary emergency department visits, hospitalizations, and procedures.[408,409] Studies of young adults with CP show they do not feel well prepared for this transition.[410–412] These studies also show that adults with CP have difficulty finding an adult doctor who is familiar enough with CP to understand the medical changes common in aging with CP and the challenges of transitioning between pediatric and adult models of care.[410,411]

Guidance is available from the AAP clinical report "Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home" (Fig 7).[408] Key recommendations include starting the preparation early (ages 12–14), assessing ongoing transition readiness, having a practice transition policy in place (a policy outlining when transfer occurs to the adult clinician and the roles of the patient, provider, and family), having a transition plan for the individual patient, creating a transition summary for the adult clinician, and identifying and communicating with that adult clinician before transfer.[408,413] The importance of time alone with adolescents who are able to communicate and an adult model of care after the age of 18 is also discussed.[408,411] The pediatrician's role as part of the youth's medical home, coordinating the preparation, planning, and transfer, is recommended.[413,414] A recent systemic review of health care transition research for youth with special health care needs showed that a "structured process" improved patient's experience, various measures of population health (including improved disease specific measures), and improved utilization of the medical system.[408,415]

Similarly, the role of the neurologist in coordination with the PCP in preparing youth with neurologic conditions for transition is discussed in a consensus statement from the American Academy of Neurology.[414] This document suggests 8 steps ("common principles") that build on the AAP clinical report. The statement includes a discussion of youth with intellectual developmental disorder, those who are capable of making decisions and independent functioning in the process of transition, and the importance of the subspecialist adding the neurologic component to the information provided to the adult clinician.[414]

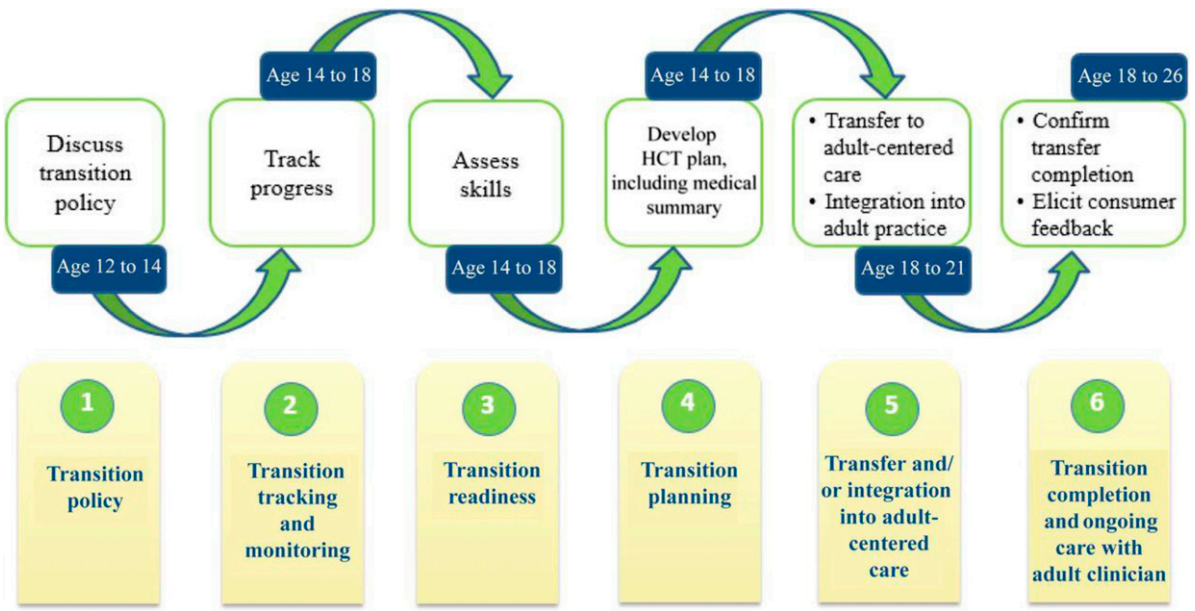

FIGURE 7

Six core elements of transition. Reproduced with permission from: White PH, Cooley WC, Transitions Clinical Report Authortin Group, American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics*. 2018;142(5):e20182587.

Guidance in the structured process of preparation, transfer, patient feedback, billing for transition preparation, and integration into the adult practice, including tools for transition, is available at Got Transition (www.gottransition.org) and the Child Neurology Foundation (www.childneurologyfoundation.org/transitions/). Coordination of care and input from all subspecialists and therapists involved in the care of a patient with CP is essential throughout the life span and very important in preparation for transfer to adult medical practices.[413]

Patients transition more successfully if they are more involved in making decisions and managing their health.[408,416] This is why a transition process that encourages the young adult with CP to become more independent is essential in those youth who are able. The role of the patient in decision making and self-management for youth with neurologic problems and CP is the focus of studies of adults, AAP statements, and the neurology consensus statements.[408,410,413,417]

Before transfer to an adult PCP, a comprehensive medical summary with input of the patient, parent or guardian, pediatrician, and pediatric subspecialists is recommended. This medical summary for youth and young adults with CP includes information regarding the patient's level of functioning,[418] current and past medical problems, efforts at tone management, surgical interventions, and complications of medications or procedures. In addition, in patients who have chronic pain, it is helpful that the summary include a description of pain level, location, and methods used to alleviate pain (and those methods that were unsuccessful). Medical comorbidities and information on the use of adaptive equipment and assistive technology is important to include.[418] Got Transition and the Developmental Disabilities Primary Care Initiative (adapted by the Vanderbilt Kennedy Center) have developed guidance for adult PCPs to incorporate youth with developmental and intellectual disabilities into their practice, with resources available at www.gottransition.org and www.iddtoolkit.org.[419,420] After transfer, it is recommended that bidirectional flow of information continues to promote integration into the adult practice and provide consultation to the adult clinician with the pediatrician if needed. The AAP clinical report on health care transition notes that increased training of adult clinicians on childhood-onset diseases is recommended and, in this context, the changes in adulthood of patients with CP.[414,421]

Preparation for Adulthood

Studies highlight the importance of being creative when it comes to planning for changes in housing, education, community resources, and insurance.[411,413] Families of youth with intellectual developmental disorder need additional preparation, including determining the level of support that their youth will need, which includes legal aspects of transition, such as guardianship, conservatorship, supported decision making, special needs trust, and advance directives.[4,408,414] This is a gap in practice, and pediatricians report that they discuss these legal aspects of transition less than 40% of the time with youth with special health care needs.[422] Consultation with a lawyer who specializes in disabilities may be helpful, keeping in mind that the least restrictive support is preferable depending on the individual's capabilities.

To enhance independence, it is recommended that youth with special health care needs have early opportunities for "life skills training" and making decisions.[412,413] Parents play an essential role in this process by providing education, opportunities for self-management, and decision making for their adolescents. In 1 study, parents regretted not pushing their children with CP to be more independent at an early age.[423] Pediatricians can support parents in their changing position during health care transition and transfer of their youth and can take an active role in recommending maximal independence (and discouraging overprotection) in those children who are capable.[424] Some believe that in those children who are able, household chores play a role in teaching responsibility, accountability, and independence. A recent study showed that children with chronic medical problems who routinely performed household chores had better health care transition readiness measures than those who did not.[425]

From age 16 years at the latest, a transition plan is included as part of the IEP. This plan is individualized for the student and recommends options for education after high school, housing, and job opportunities.[426] One study of adults with CP recommended that "self-advocacy goals and activities" be part of every youth's training and be included in the IEP provided in school.[410] The role of complexity of the medical problem, competency of the patient, and the social environment is factored into assisting patients with special health care needs to develop self-competency.[416] Those with intellectual developmental disorder, particularly those with mild impairment, can learn self-management skills to the best of their ability.[414] For youth and young adults with CP, it may be important to have family members, peers, and mentors assist with transition to adulthood.[417,427]

Evaluation of decision-making capacities can be performed and monitored throughout adolescence. If legal supports are indicated, consider having them in place when the adolescent turns 18 years of age.[428,429] This information is an important part of the medical summary communicated to the adult PCP at the time of transfer.

Other important aspects of preparing for transition to adulthood include planning housing, education, vocational training, work opportunities, therapies, insurance, supplemental security income (changes at 18 years), and transportation. These important aspects of transition depend on resources in the community and the needs and desires of the young adult.[4] A multidisciplinary team, not only in the medical home, but also in the community, is necessary to assist young adults with CP in finding available resources. Although the literature shows that there are many unmet needs, good coordination can maximize outcomes by enlisting resources that are essential for a young adult with CP to thrive.[427,430]

SUMMARY AND RECOMMENDATIONS

- All physicians who provide care for children must be familiar with the definition, manifestations, and management of CP. Primary care pediatricians, neonatologists, and other specialists who care for hospitalized newborn infants should recognize infants who have a greater likelihood for CP, use available tools to diagnose CP as early as possible, and promptly refer for therapy.
- Primary care pediatricians should implement formal developmental surveillance and screening in their practices so that children with possible motor delays such as CP can be identified as early as possible; these children should be referred promptly and simultaneously for a diagnostic assessment by a specialist and to therapy.
- When a child is identified to have CP, the primary care pediatrician should engage with the child's family and specialists to establish a patient- and family-centered care team that encourages shared decision making and interventions that promote the goals of the family.
- Pediatricians should advise families who have a child or adolescent with a diagnosis of CP about available medical, social, and educational services, such as Early Intervention, the State's Title V program, family support groups, special education services through the public school system, and Social Security as applicable.
- Pediatricians should be aware that CP is more prevalent in Black children and children who come from families with lower socioeconomic status. Recognition of these disparities should prompt physicians to identify implicit biases and barriers to screening, identification, treatment, or familial support for children with CP whose lives are impacted by social determinants of health.
- In keeping with the recommendations of *Bright Futures,* the child with CP should receive standard primary care interventions to promote health, well-being, and optimal growth and development. Preventive care includes receiving vaccinations according to the recommended childhood and adolescent immunization schedule. Primary care pediatricians should encourage their patients with CP and their families to participate in social, recreational, and community activities based on the child and teen's interests and assist with locating opportunities for adaptive sports and recreation when indicated.
- Primary care pediatricians should monitor for problems that commonly cooccur with CP, including cognitive impairments, epilepsy, sensory impairments, behavioral problems, communication difficulties, breathing and sleep problems, gastrointestinal and nutritional problems, and bone and orthopedic problems. An increased frequency of visits should be considered with referral to specialists as concern for secondary complications arise.
- When new symptoms or functional declines are seen in patients with CP, these should be investigated fully as new medical problems without assuming that they are related to the underlying CP.
- Pain is underrecognized in children with CP. All children with CP should be screened for pain. Pain in patients with limited verbal ability may be difficult to detect and may manifest as a change in behavior.
- A transition process for shifting from pediatric care to adult care should be implemented for adolescents with CP, with planning beginning by age 12 to 14 years.
- Pediatricians can advocate for their patients on an individual level and with Medicaid and other payers at a state and federal level to ensure that resources are adequate to achieve best outcomes for children with CP.

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ABBREVIATIONS

AAP: American Academy of Pediatrics
AACPDM: American Academy for Cerebral Palsy and Developmental Medicine
BiPAP: bilevel positive airway pressure
CFCS: Communication Functional Classification System
CP: cerebral palsy
CVI: cerebral visual impairment
DVT: deep vein thrombosis
DXA: dual energy x-ray absorptiometry
EI: early intervention
GERD: gastroesophageal reflux disease
GMFCS: Gross Motor Functional Classification System
ICF: International Classification of Functioning, Disability, and Health
IDEA: Individuals with Disabilities Education Act
IEP: individualized education program
NDT: neurodevelopmental treatment
PCP: primary care physician
PE: pulmonary embolism
SDB: sleep-disordered breathing
SDR: selective dorsal rhizotomy

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