Physiatrists and Developmental Pediatricians Working Together to Improve Outcomes in Children with Spina Bifida

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- Spina bifida • Physiatry • Developmental pediatrics
- Interdisciplinary care

PHYSIATRY

Physical medicine and rehabilitation (PM&R), also known as physiatry, was officially established by the founding of the American Board of PM&R in the United States in 1947.[1] However, its origins date back to ancient times with the use of physical agents and modalities to prevent and treat diseases. Physiatrists, medical practitioners of physiatry, specialize in the treatment of patients of all ages with musculoskeletal injuries, neuromuscular disorders, pain syndromes, and disabilities, and are trained in electrodiagnostic medicine. The rapid expansion of physiatry can be linked to the

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The opinions expressed are those of the authors, based on their own experience in the clinical fields of developmental pediatrics and physiatry and do not necessarily reflect the position of any professional organizations or opinions of other physicians with similar backgrounds.

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wars of the twentieth century when evidenced-based rehabilitative strategies were needed to address war casualties.

Physiatrists treat patients in outpatient clinics as well as in acute and subacute inpatient settings. The physiatrist manages specific medical problems of the patient and serves as a team leader, directing a comprehensive rehabilitation care plan that involves other clinicians including physical therapists (PTs) and occupational therapists (OTs), speech language pathologists, nurses, social workers, orthotists, nutritionists, rehabilitation counselors, neuropsychologists, rehabilitation engineers, and others whose main goal is to restore and preserve independent functioning using a team-based approach.

The overall goal of a physiatrist is to promote health and wellness while fostering independence in self-management, communication, and mobility. The physiatrist's ultimate recommendations are based on the patient's own goals and those of caregivers as well as the patient's home and community environments. Treatment plans for a particular problem are not algorithmic in nature, but rather tailored to the individual and the life roles that they fill.

Physiatrists are an essential member of the team of physicians associated with spina bifida (SB) clinics. However, for those who do not have access to a multidisciplinary SB clinic, physiatry may be an ideal medical home for the patient because a physiatrist can act as a team leader and organize the care being provided by multiple specialists in the community.

Although physicians completing a residency in PM&R are trained in pediatric and adult rehabilitation, additional training through fellowships is possible. Pediatric PM&R fellowships are available that can include further training in care of children with disabilities such as SB.

DEVELOPMENTAL PEDIATRICS

The specialty of developmental pediatrics has long been recognized. In the 1960s, pediatricians and child neurologists began to specialize in seeing children with a variety of impairments, including cerebral palsy and intellectual disability (then termed mental retardation). A strong impetus for focused and interdisciplinary care came from the Kennedy family's expressed desire to improve the lives of people with intellectual disability. Federal funding of interdisciplinary centers (university affiliated facilities, the predecessors of many current University Centers of Excellence in Developmental Disabilities) gave universities a physical setting where children could be evaluated by university-based academic physicians, therapists, and other health professionals. Most of the early physician-specialists had been trained in pediatrics and child neurology, but the focus on child development spawned training programs in what became known as developmental pediatrics.

Children's behavior was recognized as an integral part of general pediatric practice in the 1960s. As more and more children with psychosocial problems, termed the new morbidity[2] were recognized, the general pediatrician faced the prospect of being overwhelmed by the time and intensity demands of these children. Child psychiatry was a natural referral destination for children with more severe behaviors, but clearly there have never been enough of this specialty (5000 in 2003) to handle the volume of children identified with mental health problems (7–10 million children in 2003).[3] Although remaining an important part of general pediatrics, academic leaders (including Haggerty and Friedman) led a movement to develop a subspecialty of developmental pediatrics.[3] In an effort to recognize the behavioral and neurologic orientation of developmental pediatrics, the American Board of Pediatrics (ABP) has

2 subspecialties: developmental-behavioral pediatrics and neurodevelopmental disabilities. Each has their own certifying examination. Many physicians have both certifications; of those choosing one, more have opted for the developmental-behavioral designation, a reflection of the larger number of developmental-behavioral pediatrics fellowship opportunities. As in all of pediatrics, the ABP has a Maintenance of Certification (MOC) process in place to ensure that developmental pediatricians sustain skills through clinical practice, quality control, continuing education, and written test performance.

Training for both of the developmental pediatrics subspecialty certifications is currently 3 years of fellowship training after pediatric residency, although many current board-certified specialist programs began in 2001, based on a combination of postresidency training and clinical practice experience. Because of the breadth of clinical issues faced, fellowship programs inevitably have areas of emphasis but must cover training in all areas.

Developmental pediatricians assess the development and behavior of children in the context of the child's overall health and the environment in which the child lives. Areas of assessment include language, motor, attention, cognitive, and social. Clinical impressions are confirmed by formal testing done by other professionals. Interpretation of school and parent questionnaires and other input are part of the developmental pediatrician's responsibilities. The end of an assessment is a profile of the child's functioning in all relevant domains. An intervention plan can include recommendations for further assessment by health and other professionals; behavioral intervention by parents, school, and mental health professionals; use of psychotropic and other medications; and a follow-up visit. Developmental pediatricians communicate with education professionals as part of the follow-up process.

INTERDISCIPLINARY CARE OF THE CHILD WITH SPINA BIFIDA

Pediatric-oriented teams have long served children with SB. The roles of nursing, physical therapy, occupational therapy, speech language pathology, psychology, social work, nutrition, and other disciplines are critical for the effective function of these teams. This article describes the role of the generalist physician (physiatrist or developmental pediatrician) who can unite the work of these disciplines with that of surgical specialists (neurosurgeons, urologists, and orthopedists) to provide holistic, comprehensive care to children with SB.

The developmental pediatrician looks after the developmental, general medical, and behavioral needs of the growing child. Working with therapists, nurses, and social workers, this part of the interdisciplinary team takes a holistic approach to try to normalize the child's development and function at home and school. Those issues with a strong developmental theme throughout the child's life are addressed by this group: school performance, social skills, sexuality, to name a few.

In the 1990s, clinicians began to appreciate that rehabilitation medicine care was needed to supplement the more traditional interdisciplinary care provided by pediatricians and other health professionals. The heightened expectation for people with SB to function in their homes and communities drove this need for rehabilitation expertise.[4] Children with SB had attendant needs to monitor this progress in the interdisciplinary clinic as they developed. Physiatry's emphasis on function was critical in the planning for independent living and participation. The introduction of the International Classification of Functioning, Health, and Disability (ICF)[5] has reinforced this notion by offering language and terminology to describe the outcomes (participation) as well as the process (interaction of impairment with environment). Although there is not an absolute dichotomy between developmental pediatrics and physiatry, each brings its own focus to the interdisciplinary care of children with SB. Child development, behavior, anticipatory guidance, and connection to educational services are all strengths of the developmental pediatrician. Measuring and promoting function, all aimed at increased activities and participation are major contributions of physiatry.

The next sections describe the different contributions made by the 2 disciplines to the care of children with SB regarding specific issues.

Health Self-management

Developmental pediatricians are particularly oriented towards involving families in monitoring their child's condition in the context of family dynamics and normal child development. The stress of chronic illness on family members and the child may be substantial. It requires that the child and family's coping skills be monitored carefully and regularly. Acquiring health self-management skills, beginning in early childhood, requires an understanding of how the child is developing in motor and cognitive skills, as well as socially and emotionally. Helping parents let go of their tendency to maintain care for the child whom they perceive as vulnerable is an important task of health care providers. Letting the adolescent schedule appointments, directing questions to the adolescent during clinic visits, and encouraging the adolescent to manage medication refills are examples of strategies to promote self-management for adolescents. Physiatrists reinforce these same behaviors in children and families in their care.

Physical Fitness and Activity

Lifelong impairments in mobility present challenges for exercise and have resulted in alarming rates of obesity in patients with SB.[6] Adolescents and young adults tend to be physically inactive, with poor aerobic fitness and high body fat.[7] Developmental pediatricians have an orientation to normal growth that should encourage them to monitor weight gain, and its relation to nutrition and physical activity. Because nutrition is the key to weight gain, the consulting nutritionist is an invaluable member of the team. Physiatry may take the lead on choice of activities that will burn calories and minimize risk of overuse strain and injury.

Physiatric interventions include counseling and customization of creative diet and home exercise plans that use available resources and overcome barriers caused by cost, transportation, motivation, or physical inaccessibility. Constructing a team of support from caregivers, trainers, nutritionists, PTs, and/or OTs is helpful.

Neuromuscular Disorders

Musculoskeletal disorders are also common. Repetitive strain injuries, nerve entrapments, orthopedic deformities, back pain, and contractures may require conservative management by a physiatrist either after surgery or when surgical options are limited.[8] Although most individuals with SB have a lower motor neuron injury and thus do not have spasticity, increased tone can emerge for those with tethered cord syndrome.[8] Treatment is indicated when increased tone causes pain, barriers to self-care or hygiene, or when impending contracture poses a threat to optimal function or joint position. Physiatry approaches include physical or occupational therapy, oral medications, botulinum toxin, neurolysis, serial casting, and wheelchair positioning, but surgical options such as implantable pumps may be indicated in severe cases.

Mobility (Including Assistive Devices/Durable Medical Equipment)

Approximately 60% of individuals with SB use assistive technologies (AT) for mobility including manual, power-assisted, and power wheelchairs.[9] Physiatrists specialize in

AT prescription and can help patients with SB and their families navigate the difficult world of insurance claims to obtain needed equipment. An evaluation for AT should include a physiatrist, a PT or OT, a supplier, and sometimes a rehabilitation engineer. Physiatrists also work closely with vocational rehabilitation services and may consult rehabilitation counselors to aid their patients in obtaining financial support for AT needed for education or employment. Many individuals may also need other AT such as computer access equipment or mobility equipment to meet their school or work goals.

Developmental pediatrics includes the dimension of suggesting activities for which mobility might be needed: service organizations, school functions (academic and extracurricular), recreation, and age-appropriate social functions.

Pain

Through familiarity with treatment of neuromuscular pain, the physiatrist is critically important in determining options, initiating interventions, and monitoring results of pain management plans. Acute and chronic pain can pose a significant threat to independent function and quality of life. Treatment approaches are often multimodal, including psychology, medications, interventional injections and procedures, PT, OT, and many integrative, complementary, and alternative approaches. The pediatrician can help with issues of adherence by parents and patients to routines, awareness of exacerbating and ameliorating factors in the home or school environment and side effects of treatment. The pediatrician can ensure that plans are developmentally appropriate and that monitoring and reporting of interventions are shared by the child and family.

Bowel Management

Most children with SB have bowel problems, including constipation and incontinence. Neurologic deficits lead to incontinence; low abdominal muscle tone, lack of dietary fiber, and lack of physical activity contribute to constipation.[10] Bowel management is a critical component of a plan to manage skin care and to promote socialization. The pediatrician lends perspective to normal development of bowel continence and the health and social consequences of encopresis and impaction. Physiatrists will tailor a bowel program to each individual, using a combination of medications, timed toileting programs, and diet.[11] Surgical procedures are available for refractory cases. Nurses may take a lead role in teaching patients and caregivers how to carry out a bowel program.

Bladder Management

Many individuals with SB experience incontinence and urinary tract infections (UTIs) as a result of neurogenic bladder. Urodynamic testing can identify a wide spectrum of abnormalities, including upper and lower motor neuron types of bladder and urethral dysfunction.[12,13] A physiatrist or pediatrician may be involved in the basic treatment of neurogenic bladder, which includes oral medications[14] or clean intermittent catheterization (CIC). In many cases management by a urologist is necessary for surgical or interventional procedures. Asymptomatic bacteriuria in those using a CIC program does not typically require antibiotic therapy unless reflux into the ureters is present,[15] but treatment of true infections is necessary to prevent renal damage and sepsis. Several measures can be used in the prevention of UTI.[16]

The developmental pediatrician lends expertise in decisions about the child's role in managing the CIC program. With other team members (psychology, nursing, social work), the developmental pediatrician can gauge the family's readiness to begin

CIC and then oversee the child taking increasing responsibility for this process. The developmental pediatrician can share in management of UTI with the primary care pediatrician and the urologist.

Wounds and Skin Care

The causes of wounds in the SB population are often multifactorial, related to many issues such as nutritional status, pressure, shear, moisture, and even burns.[17] Vigilant skin self-inspection and care is fundamental to prevention of breakdown or complications from already open wounds. Wound care including nutritional support, pressure relief techniques, treatment of incontinence, sharp and enzymatic debridement, wound gels and barrier ointments, and dressings are conservative management tools that physiatrists implement. Serious wounds may require surgical or infectious disease consultation.

Sexuality and Personal Relationships

A comprehensive evaluation for any adolescent or adult with SB should also include an assessment of sexuality. People with SB rarely get sexual education from physicians,[18] but most individuals with SB desire more information on fertility and sexuality.[19]

These 2 issues are inextricably linked and should be addressed jointly by clinicians. Personal relationships begin in early childhood and progress to emotional and physical intimacy only after a long series of developmental steps.[20] The developmental pediatrician should monitor development of friendships during childhood and anticipate the sexual awakening that occurs with puberty. Because many children with SB may experience puberty that precedes their emotional maturity, clinicians need to be sensitive to the internal tension (normal for typical children, perhaps enhanced for children with SB[21]) caused by this dichotomy. The developmental pediatrician should lead efforts to track how a child is doing in relationship development and encourage families to allow for the kind of social experiences that will promote such development. The pediatrician must allow the parent to find the delicate balance between safe and developmentally appropriate social experiences for the child with mobility limitations. Physiatry can lend expertise in movement, positioning, and sensation to the child learning about function and self-management of sexual organs, bowel, and bladder.

Physiatrists are trained to understand reproductive issues and how they relate to spinal cord dysfunction and can be a valuable educative source for patients on this topic.

Education

Developmental pediatricians have special expertise in assessing the educational needs and proposing interventions. Using input from psychologists, speech and language pathologists, and special educators, the developmental pediatrician should provide input into the individualized education plan (IEP). Their experience in interacting with the school, for both assessment and planned interventions, should support the parent and child in determining the best IEP. Other complicating behaviors (inattention, depression, acting out) can be assessed and followed by the developmental pediatrician. If the child does not qualify for special education and an IEP, the developmental pediatrician can help parents request a 504 assessment, which could also yield an individualized plan.[22]

Preparation for Employment

Developmental pediatricians know the adolescent's academic potential and can discuss career opportunities with the adolescent and parents. The developmental pediatrician should monitor the required transition plan if the child has an IEP and also monitor and encourage the development of age-appropriate home responsibilities, which can indicate an adolescent's readiness to take on more adult responsibilities. The physiatrist should take the lead on the accommodations that need to be made for the adolescent to have volunteer and work experience, which may include transportation to the work site and technological accommodations within the work place (for mobility, communication, or computer access). Job coaching and mentoring can be directed by either the developmental pediatrician or physiatrist. When services and funding from the state's Vocational Rehabilitation Department need to be accessed, the physiatrist often has the best experience to handle this. Physiatry's orientation to restoring functional skills (driving, mobility) in people with spinal cord injury could be invaluable in establishing similar skills in adolescents with SB.

Working Together

Developmental pediatricians excel at the developmental, behavioral, and educational aspects of SB care. Their training in normal development helps guide monitoring of the progress children make in many of the important domains described in the Life Course Model for SB (see the article by Swanson in this issue). Social and behavioral adjustment is monitored using parent interviews and administration of a formal behavioral rating instrument (with the aid of psychologists). School readiness and watchful anticipation for learning disabilities, language problems, and other executive function disorders are monitored with information from schools and language therapists. Co-occurring problems with sleep, attention, and depression suit the training of the developmental pediatrician. The developmental pediatrician can also help implement plans for shunt management, bowel and bladder management, and skin care that may be initiated by other professionals. When a primary care pediatrician is not strongly involved, due attention to coordination of care and linkage to community resources may be the responsibility of the developmental pediatrician.

Physiatrists play a key role in treating conditions such as skin breakdown, neurogenic bowel and bladder, and musculoskeletal conditions, while focusing on how these conditions affect independence and function. A physiatrist aims to improve health and wellness through promotion of activity and independent mobility and to lessen the effect of secondary disabling medical conditions. The physiatrist views the patient as a whole, rather than an organ system, and a person within the broader context of their environment and life roles. With this view, and by acting as a coordinator of many disciplines, the physiatrist can help to ensure that the patient's care plan is suited to promote the patient's goals and the highest level of independent functioning possible.

SUMMARY

Based on the experience of 2 physicians from physiatry and developmental pediatrics, this article proposes a framework for improving care and outcomes for children with SB. The combined skills of physiatrists and developmental pediatricians, along with other disciplines, can form the ideal team to manage the complex issues faced by this population. The developmental pediatrician is best suited for directing care for younger children through the elementary and middle school years, during which time behavioral and educational issues are prominent. As the child assumes more responsibility for self-management in adolescence, the physiatrist is ideally suited to providing major clinical input that improves functional outcomes. The addition of the discipline of physiatry to traditional, developmentally oriented pediatric interdisciplinary teams can add the much needed dimensions of activity and participation, and improve functional outcomes at the adult level by encouraging activities in adolescence that lead to full participation in adulthood.

REFERENCES

1. Opitz JL, Folz TJ, Gelfman R, et al. The history of physical medicine and rehabilitation as recorded in the diary of Dr. Frank Krusen: part 1. Gathering Momentum (the Years Before 1942). Arch Phys Med Rehabil 1997;78:442–4.
2. Haggerty RJ, Roghman KJ, Pless IB. Child health and the community. New York: John Wiley; 1975. p. 94–5.
3. Haggerty RJ, Friedman SB. History of developmental-behavioral pediatrics. J Dev Behav Pediatr 2003;24:S1–17.
4. Kinsman SL, Levey E, Ruffing V, et al. Beyond multidisciplinary care: a new conceptual model for spina bifida. Eur J Pediatr Surg 2000;10(Suppl 1):35–8.
5. Lollar DJ, Simeonsson RJ. Diagnosis to function: classification for children and youths. J Dev Behav Pediatr 2005;26(4):323–30.
6. Dosa NP, Foley JT, Eckrich M, et al. Obesity across the lifespan among persons with spina bifida. Disabil Rehabil 2009;31(11):914–20.
7. Buffart LM, Roebroeck ME, Rol M, et al. Triad of physical activity, aerobic fitness and obesity in adolescents and young adults with myelomeningocele. J Rehabil Med 2008;40(1):70–5.
8. Dicianno BE, Kurowski BG, Yang JM, et al. Rehabilitation and medical management of the adult with spina bifida. Am J Phys Med Rehabil 2008;87(12):1027.
9. Dicianno BE, Gaines A, Collins DM, et al. Mobility, assistive technology use, and social integration among adults with spina bifida. Am J Phys Med Rehabil 2009; 88(7):533.
10. Sullivan PB. Gastrointestinal disorders in children with neurodevelopmental disabilities. Dev Disabil Res Rev 2008;14(2):128–36.
11. Bischoff A, Levitt MA, Bauer C, et al. Treatment of fecal incontinence with a comprehensive bowel management program. J Pediatr Surg 2009;44(6): 1278–84.
12. Kessler TM, Lackner J, Kiss G, et al. Predictive value of initial urodynamic pattern on urinary continence in patients with myelomeningocele. Neurourol Urodyn 2006;25(4):361.
13. Sakakibara R, Hattori T, Uchiyama T, et al. Uroneurological assessment of spina bifida cystica and occulta. Neurourol Urodyn 2003;22(4):328–34.
14. Chancellor MB, Anderson RU, Boone TB. Pharmacotherapy for neurogenic detrusor overactivity. Am J Phys Med Rehabil 2006;85(6):536–45.
15. Ottolini MC, Shaer CM, Rushton HG, et al. Relationship of asymptomatic bacteriuria and renal scarring in children with neuropathic bladders who are practicing clean intermittent catheterization. J Pediatr 1995;127(3):368–72.
16. Biering-Sørensen F. Urinary tract infection in individuals with spinal cord lesion. Curr Opin Urol 2002;12(1):45.
17. Balakrishnan C, Rak TP, Meininger MS. Burns of the neuropathic foot following use of therapeutic footbaths. Burns 1995;21:622–3.
18. Cardenas DD, Topolski TD, White CJ, et al. Sexual functioning in adolescents and young adults with spina bifida. Arch Phys Med Rehabil 2008;89(1):31–5.

19. Sawyer SM, Roberts KV. Sexual and reproductive health in young people with spina bifida. Dev Med Child Neurol 1999;41(10):671–5.
20. Blum RW, Resnick MD, Nelson R, et al. Family and peer issues among adolescents with spina bifida and cerebral palsy. Pediatrics 1991;88(2):280–5.
21. Sawin KJ, Buran CF, Brei TJ, et al. Sexuality issues in adolescents with a chronic neurological condition. J Perinat Educ 2002;11(1):22–34.
22. American Academy of Pediatrics: The pediatrician's role in development and implementation of an individual education plan (IEP) and/or an individual family service plan (IFSP). Pediatrics 1999;104(1):124–7.