FROM THE EDITORS’ DESK

21st Century Challenges to the Provision of Health Care to Adults With Spina Bifida: A Rehabilitation Approach

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In 1999 in *Archives of Physical Medicine and Rehabilitation*, Joel DeLisa, MD,1 discussed “Issues and Challenges for Physiatry in the Coming Decade.” He proposed that physiatrists should play a key role in the coordination of care for adults with disabilities from conditions such as spina bifida. The *Archives* has published a series of articles that are instrumental in guiding how physiatrists can be leaders in this area. In this editorial, I would like to highlight these articles from *Archives* and some additional articles, as a special topic collection.

First, however, we must delineate the similarities and differences between a “medical home model” of care and a “specialty medical home.”2(p1493) The generally accepted concept of a medical home is that a primary care practice is the hub. However, in some medical conditions, a specialty practice, rather than a primary care practice, may be a more appropriate hub. For example, in persistent mental disorders, a psychiatric practice may be best suited to serve as a specialty medical home.3 While the goal of the specialty medical home is to provide patient-focused, coordinated care at first contact, a comprehensive care model must still include primary care practice for treatment of common medical conditions (eg, diabetes, hypertension), routine immunizations, and screening tests. Yet, in a specialty medical home, the coordination of care responsibility shifts from primary care providers to the clinicians who are providing treatments for the conditions most often responsible for morbidity and hospitalization.

Almost 15 years after DeLisa’s article was published, we still have no clear medical home model for adults with disabilities such as spina bifida. Children with spina bifida often receive care in multidisciplinary clinics, many of which are affiliated with urban teaching hospitals.4 Many multidisciplinary clinics do not survive because of issues with financial support and reimbursement, program structure, and challenges in staffing.5 Of the surviving clinics, only a subset provides care to adults. That leaves many young adults who transition out of a pediatric setting without adult-centered health care. Even in settings where pediatric specialists continue to provide care to adults, they must be equipped to handle issues that are unique to adults.6-9 Safe transition from a pediatric setting to an adult-care provider, however, is necessary to optimize health.10 Binks et al10 provide solid evidence that the transition process should include sufficient preparation, flexible timing of the transition, care coordination, visits to an outpatient “transition clinic,”10(p1067) and interested adult-centered health care providers who will receive these patients.

When a young adult transitions into the confusing and disjointed system of adult health care and no one assumes responsibility for coordination of care, 3 important concepts of care can fall through the cracks.11 The first is *prevention*. About one third of hospitalizations of adults with spina bifida in the United States are due to conditions that could potentially be prevented with better outpatient care.12 Two of these conditions are urinary tract infection (UTIs) and skin wounds. Sepsis from UTIs and wound infections is responsible for the most in-hospital deaths. Potentially preventable conditions that result in hospitalization are most common in adults with spina bifida who are younger than 51 years and in those treated in rural or urban nonteaching hospital settings.12,13 The problem is similar in Canada, where young adults with spina bifida access health services more often than age-matched peers, but few are treated in a medical home model.17

The second concept is the accumulation of *secondary conditions related to aging* that are responsible for medical and functional decline.15 Overuse injuries such as rotator cuff syndrome, osteoporosis,16 obesity, and low physical activity levels are just a few examples.15 Low levels of physical activity in spina bifida have been linked to dyslipidemia, hypertension, smoking, and evidence of cardiovascular disease risk factor clustering.17 In turn, obesity is a predictor of transition from ambulation to wheelchair use.18

The third concept is the treatment of *sequelae of neurologic conditions* to preserve quality of life. Sexual dysfunction and neurogenic bowel are just 2 examples. Relationships and sexuality are important to adults with spina bifida but rarely addressed by other health care providers.19 Sexual dysfunction is treatable and yet is undertreated in this population, leading to participation in risky behavior.20 A comprehensive approach to treating neurogenic bowel can also improve continence and quality of life.21 Preventing and treating conditions like UTIs and wounds, managing disability and impairment from the secondary conditions

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of aging, and treating neurologic sequelae are clearly within the scope of physiatric practice, particularly for those trained in spinal cord injury care. When taken together, the articles in this special topic collection provide strong evidence that in the absence of a multidisciplinary clinic, physiatrists can care for many of the common issues facing adults with spina bifida. Working with a primary care physician and providing care coordination with neurologic, urologic, orthopedic, and other surgical specialists, the physiatrist can be central in a comprehensive, patient-centered care model. Reducing the number of secondary medical conditions with proactive and preventive approaches could potentially reduce the morbidity, mortality, and cost of health care for this group of patients while improving their quality of life.

Barriers exist for implementation of this model. Patients and other specialists are often not knowledgeable about the skills and expertise of physiatrists. Patients who live in underserved and rural areas may lack access to physiatrists. Not all physiatrists may be sufficiently trained to deal with the complex problems patients with spina bifida face, and newly trained physiatrists may be drawn to areas within rehabilitation medicine where reimbursement is higher.

We as physiatrists can and should become leaders in the care of these patients. There are many ways to become involved. We can incorporate the care of the adult with spina bifida into the curricula of residencies and spinal cord injury fellowships within physical medicine and rehabilitation. We can hold educational symposia on spina bifida topics at our professional meetings. We can educate our colleagues about our expertise in treating disability-related issues and create referral networks and resources. We can participate in clinical research. We can become involved in professional organizations such as the Spina Bifida Association. We can work with insurers and health systems to develop new specialty medical homes for patients, innovative reimbursement systems, and telemicine systems to enhance patient care and for physician-to-physician consultation in remote areas. Pediatric providers can incorporate evidence-based transitional care plans into our practices. We can develop “transition clinics” in outpatient settings. We can act as interested adult-centered health care providers who will receive these patients when they transition from pediatric care. Often, the biggest impact and paradigm shifts can be made when health care is in flux. It is time now for us to act.

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