The Pediatric Neurosurgical Patient: The Challenge of Growing Up

Harold L. Rekate, MD

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Having practiced pediatric neurosurgery for more than 30 years, I have developed a keen interest in problems related to what happens to my patients after they become adults. My practice is within a general hospital with a long-standing commitment to tertiary pediatric neurosurgical care. Therefore, my patients who remain in Phoenix are not required to seek another neurosurgeon to care for their congenital neurosurgical problems. When my mature patients leave Phoenix, I have found it very difficult to help them find care for their complicated problems in other geographic areas. In an attempt to help develop a transition plan for such patients, I asked for and received permission to convene a meeting during the annual meeting of the Joint Section of Pediatric Neurological Surgery of the American Association of Neurological Surgeons (AANS) and Congress of Neurological Surgeons (CNS) in Denver in 2007. As a result of this meeting and the interest that it generated, I was asked by the then-Chairman of the Joint Section, Professor I. Richmond Abbott, to give the prestigious Donald D. Matson Honored Lectureship at the 2008 annual meeting of the AANS held in Washington, DC. The assessment and study of the challenges associated with transitioning neurosurgical care from pediatric neurosurgeons to general neurosurgeons motivated this review.

My original intent was to evaluate the role of the various neurosurgical organizations in facilitating the transition of care of these complex patients. My analysis of the roles of these organizations forms the core of this review. Soon, however, it became obvious that the problem of transition was extremely complicated, with no simple resolution. The strategies that might prove useful depended on various political, economic, and geographic issues, as well as on the individual personalities, resources, and philosophies of the many stakeholders involved.

In this review, I have attempted to define the stakeholders in the problem of transition, the challenges facing each, and potential solutions. As a prelude to this study, I thought it necessary to first define why there is a problem. What makes children who have grown up with neurosurgical problems different from adults who develop these or related problems?

**Congenital Neurosurgical Problems in Adults**

The subspecialty of pediatric neurosurgery justifies its existence in 2 ways. The place of practice for pediatric neurosurgeons is usually, although not exclusively, within children's hospitals. More importantly, however, the disease processes that pediatric neurosurgeons treat differ substantially from those faced by general or adult neurosurgeons. The types of brain tumor that pediatric neurosurgeons treat are histologically, anatomically, and pathophysiologically distinct from those treated by general neurosurgeons. Head injuries in children are less likely to result in mass lesions as compared to those suffered by adults. The developmental aspects of the pediatric spine and the congenital and hereditable diseases
seen in these patients render the decision-making process in children significantly different from that found in adults. Congenital anomalies of the nervous system are rarely corrected by a single operation. Instead, they tend to remain a challenge for patients throughout their life. Finally, hydrocephalus can develop at any age of life. However, hydrocephalus that develops during infancy is in many ways more challenging than that which develops during adulthood, and those challenges plague patients throughout their lives. Spina bifida and hydrocephalus are 2 problems occurring in infancy, potentially consistent with a normal or near-normal length of life in some patients. These conditions emphasize the unique, lifelong challenges associated with patients whose neurosurgical care begins in infancy.

Spina Bifida
In the past, myelomeningocele, spina bifida aperta, or open spinal neural tube defects were the most common severe birth defects found in humans. With the discovery that folic acid supplementation in women before conception dramatically lowered the chance that a child might be affected by spina bifida and with the institution of routine screening for maternal alpha fetal protein to detect these abnormalities early in gestation, the incidence of spina bifida in the United States has decreased significantly over the last few decades. Nonetheless, the management of this complex condition, whether in older patients with the condition or in newborns afflicted with this congenital anomaly, remains a significant part of the practice of most pediatric neurosurgeons. With the development of shunting systems for the management of hydrocephalus in these infants, large numbers of children with spina bifida who formerly would have died were cared for by multiple different specialties. By the late 1960s, spina bifida became the model for patients with complications whose management required coordination in a multidisciplinary setting. In the United States, these clinics were typically founded within state-funded programs referred to as “crippled Children’s Services.” These services were primarily developed for the care of patients with cerebral palsy and were staffed by orthopedists. Subsequently, the programs broadened their perspectives to include a large number of children with congenital anomalies of many organ systems. Caring for infants and children with spina bifida in multidisciplinary clinics became the standard of care. With time it became evident that it was essential for urologists, orthopedists, neurosurgeons, pediatricians, and rehabilitation specialists to work together and to communicate with each other to maximize the functional capacity of the affected individual. For instance, secondary tethering of the spinal cord in this condition often manifests with the sudden failure of the patient to remain dry on clean intermittent catheterization. It is, therefore, likely that the condition will first be recognized by the urologist caring for the patient. Alternatively, a tethered spinal cord manifests as a deterioration in the strength of the distal segments of the remaining spinal nerve roots, and is therefore recognized first by an orthopedic surgeon. Without the interaction among the specialists involved in these patients’ care, the diagnosis of recurrent tethered cord would be delayed and permanent loss of function would likely result.

Kaufman et al2 reported the follow-up of patients with spina bifida in St. Louis when the multidisciplinary spina bifida clinic there was disbanded. These outcomes highlight the importance of interaction among these specialists in the functional outcome of these patients. Although the involved specialists remained available and there were no insurance difficulties for the patients obtaining care, the patients did not seek care in a timely manner. This lack of care led to acute problems as the patients reached adolescence, and the rate of serious complications, such as the need for nephrectomy and amputation, increased markedly. From a financial perspective, this study showed that considerable amount of money was saved in the first 3 years because preventive care and screening studies decreased. After 3 years, however, the cost of care and the serious nature of complications overwhelmed this early saving. It should be noted that coordinated care for adults with spina bifida through a multidisciplinary clinic is available in a very few centers in the United States.

On the basis of this study, we attempted to establish an adult spina bifida clinic on the model of the multidisciplinary spina bifida clinic run through Children’s Rehabilitative Services of the State of Arizona. By statute, all patients born with spina bifida in Arizona are eligible for care in this state-run clinic until the age of 21 years. The clinic involved a cooperative program through the primary payer for adults with spina bifida who had received care during childhood, that is, Medicaid through Mercy Care Arizona Health Care Cost Containment System program (a Medicaid health maintenance organization [HMO]); St. Joseph’s Hospital and Medical Center, the home of the Barrow Neurological Institute; the medical staff of the Children’s Rehabilitation Service (CRS); and the Arizona Spina Bifida Association. Because the medical care for these young adults had been provided at St. Joseph’s Hospital and Medical Center during childhood, and because these patients had insurance by the single Medicaid HMO, this clinic represented a continued medical home for these patients, with the hospital supplying some support services to the clinic. The clinic began as a pilot study in which 10 patients (6 women, 4 men, 23-48 years old) who were previously treated through Children’s Rehabilitation Service received coordinated care for a year. Three patients were employed and lived independently. Eight patients required neurosurgical intervention, and 4 required treatment for decubitus ulcers. The cost of care for these 10 patients in this year was considered unacceptable by the payer, and the idea of creating a multidisciplinary clinic had to be abandoned. An important result of the study was defining the incidence of severe obesity in the adult population (8 of 10 patients) and its effect on the health and functional abilities of these adults.

Hydrocephalus
Hydrocephalus that begins in infancy is significantly different from that which begins in adulthood. In adulthood, the causes of hydrocephalus are relatively few, such as tumor,
meningitis, and hemorrhage. The point of obstruction in adults with hydrocephalus can usually be demonstrated with a high level of accuracy and represents a specific point of obstruction. In adults who develop hydrocephalus, most pathologies lend themselves to treatment with endoscopic third ventriculostomy (ETV).^{4,5}

Not all patients first treated in adulthood actually develop hydrocephalus at that point. Decompensation of chronic compensated hydrocephalus is a completely different condition, which is increasingly being recognized as contemporary imaging studies are used more often to evaluate patients with headaches, minor head injuries, and seizures. This condition has been termed long-standing overt ventriculomegaly of the adult. Most of these patients have triventricular hydrocephalus and not aqueductal stenosis. The aqueduct is often functionally closed by the hydrocephalus, but opens after treatment, by either endoscopic third ventriculostomy or shunt.\(^7\)\(^8\)

Hydrocephalus in infants is much more complicated. Its potential causes not only relate to the 3 causes of hydrocephalus in adults (ie, tumor, hemorrhage, and infection), but it is also caused by abnormalities of brain development that obstruct the flow of cerebrospinal fluid (CSF). These obstructions may be difficult to define radiographically. For example, in the case of hydrocephalus related to spina bifida, there are 4 potential points of obstruction to CSF flow related to the Chiari II malformation. It is difficult, if not impossible, to determine which points of obstruction are causing the hydrocephalus in an individual patient, and each patient can have multiple points of obstruction, making the management of the hydrocephalus extremely difficult.\(^3\)\(^5\)\(^9\)

The size of the ventricle normalizes in an adult who develops hydrocephalus and is treated with a shunt. When the shunt fails, the size of the ventricles again expands. This scenario is not necessarily true of adults who developed hydrocephalus as infants. Engel et al,\(^10\) who first recognized this nonresponsiveness of the ventricles to shunt failure, labeled this confusing condition normal volume hydrocephalus (NVH). NVH, or nonresponsive ventricles, occurs in 20%-25% of patients with infantile hydrocephalus, regardless of their age at the time of shunt failure.\(^11\) A 30-year-old patient with spina bifida, or one treated within the first few months of birth for triventricular hydrocephalus and a rapidly increasing head circumference, may exhibit no change in the size of that patient’s ventricles, despite markedly increased intracranial pressure (ICP). On occasion, a young woman with hydrocephalus related to spina bifida was found to have ICP of 80 mm Hg as measured intraparenchymally.\(^12\) If both jugular veins are ligated in such adults (eg, during radical neck dissections), these adults develop a type of pseudotumor cerebri with no increase in ventricular size, but very high ICP. If obstruction to venous outflow occurs in infants whose fontanel and sutures are open, CSF cannot be absorbed because of high venous pressure. Hydrocephalus develops, and the size of their head increases rapidly. We measured the pressure in the sagittal sinus of 12 patients with NVH, and all had marked increases in sagittal sinus pressure from some obstructive process.\(^13\) When the condition is severe, patients can have frequent failures of their ventricular catheters and can develop severe slit ventricle syndrome. These patients often require treatment with strategies that access the cortical subarachnoid space using lumboperitoneal shunts or shunts that access the cisterna magna.\(^12\)\(^14\)\(^15\)

Other Chronic Conditions

Other chronic conditions managed by pediatric neurosurgeons can be mentioned in this context. Examples include craniofacial disorders, late effects from the treatment of brain tumors in the very young, and occult dysraphism. It is not unusual for adult patients with hallmarks of dysraphism to show signs of deterioration as adults. The decision among various treatment options may differ depending on the patient’s age. However, the thought process, surgical anatomy, and surgical techniques are familiar to pediatric neurosurgeons.

Challenges for the Pediatric Neurosurgeon

In the United States, the beginning of pediatric neurosurgery as a distinct specialty dates to the founding of the Section on Pediatric Neurological Surgery of the AANS in 1972. This organization is now a function of both the AANS and CNS and is called the Joint Section. At the time of its establishment, a distinct and identifiable pediatric neurosurgical service existed in very few centers. Fellowships in this field were only offered in 2 centers in North America: The Hospital for Sick Children in Toronto, under Drs E. Bruce Hendricks, Harold Hoffman, and Robin Humphreys; and Children’s Memorial Hospital (Northwestern University) in Chicago, under Dr Anthony Raimondi.

In the late 1960s and early 1970s, interest in pediatric neurosurgery increased to a great extent, stimulated by the development of the valve-regulated shunt for the treatment of hydrocephalus. Suddenly a large number of infants were given hope of survival and functional life where none had existed before. Successful shunting also led to an aggressive posture with respect to the management of spina bifida and to the development of multidisciplinary clinics for the management of these and other complex birth defects. Neurosurgeons involved in the care of these patients confronted unexpected problems, such as insidious shunt infections, that were a challenge to diagnose and treat. Opportunities to share experiences resulted in the establishment of the Joint Section in North America and of the International Society for Pediatric Neurosurgery globally.

It became obvious that the spectrum of neurosurgical disease in children differed greatly between children and adults. Most of the work of a pediatric neurosurgeon is related to hydrocephalus in some way. Craniosynostosis and tethered spinal cord are rare in the practice of general neurosurgeons. Histologically, brain tumors in children are different from those in adults. The prognosis for life tends to be better than in adults, but the biological cost to patients is greater.
The Personality of a Pediatric Neurosurgeon

The life and career of a pediatric neurosurgeon differ greatly from those of general neurosurgeons and other neurological subspecialists. Although an oversimplification, pediatric neurosurgeons manage a disease, whereas other neurosurgeons primarily focus on performing procedures. Pediatric neurosurgeons often care for adolescents whose children have come to their attention but are not their own. For their part in the patient’s life. Both the parents of these children and their pediatricians demanding, intimate, and personal relationship with the neurosurgeon caring for the child, especially during acute stressful situations. I must say with some pride that pediatric neurosurgeons tend to view their careers as a calling. As stated so well by the British poet Gerard Manley Hopkins, “What I do is who I am, it is why I came.”

Disease management is associated with a substantial cost. In pediatric neurosurgery, the number of patient encounters per surgical procedure is likely to be more than twice that in general neurosurgery. The reimbursement system, especially in a specialty such as neurosurgery with high malpractice rates and other overhead costs, is geared to the surgical procedure. Less credit and compensation are given for the management portion of the process. Consequently, reimbursements for pediatric neurosurgeons are somewhat lower as compared to general neurosurgeons, and particularly in comparison with neurosurgeons specializing in spinal surgery. A study presented by Dr. Susan Durham from Dartmouth at the 2007 meeting of the Joint Section in Miami emphasized this issue. She reported that more than half of the pediatric neurosurgeons responding to a questionnaire reported that their income was either provided by the hospital, university, or substantially supported by them. Fewer than 1 in 4 pediatric neurosurgeons were in a situation in which all income was derived from patient billings (Durham S, personal communication, 2007).

Current Practices of Pediatric Neurosurgeons Regarding Transition

During the 2008 meeting of the American Society of Pediatric Neurosurgeons (ASPNS) in Cabo San Lucas, Mexico, I polled the membership in attendance about their views and practices related to the issues of transition of their patients. About 70 members responded to the questionnaire, but not all respondents answered all questions. The findings were discussed at the end of the meeting. Of 67 responders, 52 practiced in free-standing children’s hospitals where they could not continue to care for patients beyond a certain age. Nine practiced in general hospitals with pediatric units, and 6 practiced in a facility with a hospital within a hospital. Therefore, 78% of the responders, who represented about half of the membership of the ASPNS, could not continue to care for their patients after they reached maturity.

The age at which an individual became too old for a specific institution varied, but it was usually at 18 or 21 years. Although 89% of these hospitals accepted patients aged > 18 years, only 44% accepted patients > 21 years. Of those, half would encourage the admission of any patient > 21 years. These results indicate that the practice of most pediatric neurosurgeons is limited to children’s hospitals. They rarely, if ever, care for adults, even those who have been in their practice for decades. This situation is primarily a reflection of the setting in which these physicians practice.

In answer to the questions related to preparing their own patients for this transition, fewer than half of the respondents had a policy to begin discussions regarding transition of care. Only 1 in 4 was aware that the American Academy of Pediatrics (AAP) advocated beginning the process at the age of 14 years. Sixty-four percent of responders had identified a general neurosurgeon or a group to which their patients would be referred. For only the case of 1 in 4 responders was there coordinated care for adult spina bifida patients in their catchment area.

Most neurosurgeons responding to the questionnaire were concerned about the effect of this transition on their patients. After their transition, 75% of the respondents would take advice calls from former patients, and all respondents would take consultation from general neurosurgeons calling about an adult patient with a pediatric neurosurgical problem (Rekate H, unpublished data, 2008).

The Role of the Patient and Family During the Transition

The definition of an adult is someone who makes his or her own decisions and takes responsibility for his or her own actions. Part of becoming an adult relates to making decisions about one’s healthcare. For patients with special healthcare needs (SCNs), this process is frightening and difficult. Those with severe disability may have to continue to rely on their parents to provide this type of care until the parents are infirm. It is rare for children with SCNs to become independent in the same time frame as unaffected individuals. In this context, independent living is challenging and difficult for families. Parents have made decisions that have affected their child’s life. For many parents with seriously disabled children, caring for their child has been a full-time job. Physicians caring for adolescents with SCNs are likely to discuss the transition with parents without talking to the patient. Overall, adolescents accept the decision reached by their parent and physician. The goals of surgery that affect a patient’s care are those agreed upon without buy-in from the patient. This process must change as patients reach maturity.

Preparing for the transition should begin early. In its important position paper on transition of care, the AAP stated that preparation for transition of care should begin at about the age of 14 years. Doing so makes great sense for a variety of reasons. Adolescence is, and should be, about growing up with the aim of becoming an adult. At this point, adolescents with SCNs should begin to educate themselves about their conditions. For example, adolescents should understand what caused their hydrocephalus, what care is needed to remain healthy, what could happen if care is not sought or made available, what kind of shunt they have, their past
treatment, where they can receive emergency care, and whom to contact for questions. A written document with this information is useful and forms the basis of a health record that the patient should keep up-to-date and accessible. Without being excessively confrontational, adolescents should make it clear that they wish to be involved in the discussion and to help make the important decisions about their healthcare.

Phases of Life Regarding Transition

Fourteen years of age seems to be a break point in making healthcare decisions. Patients have reached almost their adult height. The physiology of most organ systems has matured enough, and so the reaction to treatment, including pharmacologic treatment, is similar to that of adults. If patients with SCNs relocate after age 14 and seek care from practitioners at a free-standing children’s hospital, they will likely experience the difficulties of transitioning again in a few years. Therefore, it might be better to use such opportunities to identify a care system that can care for the patients after they reach the age at which care in a Children’s Hospital becomes problematic (ie, age 18 or 21 years, depending on the policies of the individual children’s hospital).

In this situation, where should care be sought? A children’s hospital that shares facilities with a general hospital and that can share expensive technologies is one answer. Do pediatric neurosurgeons participate in the care of young adults in adult clinical units? Primary Children’s Hospital in Salt Lake City is handling these problems in a unique and experimental way. They have opened a unit for young adults with SCNs that began in childhood. The unit cares for patients until the age of 40 years. In large cities or urban areas, general hospitals often have units for the care of children. In some of these facilities, general neurosurgeons show a continuing interest and a commitment to pediatric neurosurgery and care for both children and adults with the problems usually associated with childhood. These neurosurgeons are often called pediatric and congenital neurosurgeons. My first acquaintance with this apt term was through Dr Mark Luciano, the pediatric and congenital neurosurgeon at the Cleveland Clinic.

The next critical period is when patients are 18 years old. At this point, patients are legally adults. They can sign authorizations for medical care, make contracts, and so on. At this age, patients are assumed to be capable of making their own decisions. Without a legal durable medical power of attorney, parents can no longer sign permissions for their child’s medical treatment. On the basis of some interpretations of the Health Insurance Portability and Accountability Act, information cannot be given to the family without the patient’s approval. Patients in this age group are more likely to travel unscored, and some attend college. At this age, these patients must define who can make medical decisions on their behalf, if needed. A parent or spouse should have a durable medical power of attorney on file. Informed consent should be documented. The Hydrocephalus Association has prepared a booklet outlining the steps that need to be taken to ensure that the appropriate persons can make medical decisions and can give and receive medical information for patients with SCNs.

Ms Cynthia Solomon, who along with Ms Emily Fudge founded the Hydrocephalus Association, has developed a computerized platform for the maintenance of personalized health records online. The information is secure, password protected, and the property of the patient. It can be accessed directly from the Internet and can be updated and modified by the individual. It is therefore available anywhere in the world, at any time. Using this platform, the patients may organize their information to optimize their medical care when needed. For patients with hydrocephalus, the platform is available using the Web site http://www.Mybrain.org. For patients who travel frequently, are at college, or tend to relocate, this platform is an extremely powerful tool.

For many patients with SCNs, the next phase in life begins at the age of 21 or 25 years, depending on the policies of the hospital. If care is being provided at free-standing children’s hospitals, the patient must transition to adult-center care. In most situations, this means changing neurosurgeons. As shown by the responses to the ASPN questionnaire, fewer than 1 in 4 pediatric neurosurgeons will provide care to their own patients after those patients are in adult institutions. Preparing for this transition requires considerable work. Collecting 21 years of x-rays, computed tomography scans, magnetic resonance images, and operative notes in a box for the adult neurosurgeon to review in preparation for a patient’s initial consultation is an unreasonable expectation. Yet, patients must be prepared for that first consultation. They need to know their history, the results of their earlier treatments, what they want from the relationship, what they need to do in an emergency, and how to obtain answers to questions. If the adult neurosurgeon wishes to delve more deeply into their history, patients need to be organized enough to find answers quickly. This relationship takes work to cultivate, but doing so is worth the effort. Patients need to remember the number of times that they have been kept waiting by their pediatric neurosurgeon. Neurosurgeons who care for shunts have little control of their time or schedules. Emergencies are an integral part of their life. Delays are not caused by their rudeness, but by their profession. In a growing number of practices, the point person for the relationship is a nurse practitioner or physician’s assistant. These trained professionals add immensely to the care of patients with chronic conditions such as hydrocephalus and spina bifida.

The Role of Organized Medicine

Associations of medical professionals usually share 2 goals: to ensure excellence in care for the patients served by the members of the association, and to support and improve the working environment of the members providing this care.

The American Academy of Pediatrics

To meet these goals, the AAP offers programs to improve patient care, educate physicians, and advocate for their mem-
bers and their patients. In 2008, the AAP chose the problems related to transition of care as one of the most important challenges facing pediatric care in the United States. This problem has long been discussed at the AAP. The Academy published 2 sets of guidelines on transition of care, one in 1997 and the other in 2006.\textsuperscript{17,18} In these documents, the Academy recommended that physicians encourage their patients to begin developing a plan for transition beginning at the age of 14. It also defined an ideal "medical home" model of care, whereby pediatric and adult practitioners would be linked to provide a seamless transition. Several models were proposed, including having an adult practitioner or a specialist in each pediatric group for this purpose. The guidelines were a joint function of the AAP and the American Academy of Family Physicians. How such a medical home model would work efficiently depended on the geography of the region or the proximity of the children’s facility to the area where the young adults would receive care.

The Section on Neurological Surgery of the AAP, chaired until recently by Dr Joseph Platt, and now led by Dr Mark Dias, has been a leader in emphasizing the importance of planning for transition and defining strategies to deal with this issue.

**The Joint Section**

The Joint Section is a function of both major neurosurgical organizations. The objectives of the organization are to provide an intimate forum for the exchange of ideas related to pediatric neurosurgery and to further education, research, and patient care for patients with pediatric neurosurgical conditions. In 2008, the Joint Section had 391 active members as compared to the approximately 150 members of the ASPN. The qualifications for membership in the Joint Section are limited to being a member of the AANS or CNS and a wish to join. In contrast, the ASPN requires its members to be committed to a career that is devoted almost exclusively to the care of children. About 240 members of the Joint Section do not belong to the ASPN. Most of these individuals likely practice a mixture of adult and pediatric neurosurgery. In my opinion, as voiced in my Matson Award Lecture at the AANS meeting in 2008, we must capture this group to ensure quality care for adults with pediatric neurosurgical conditions. I have recommended to the Joint Section that the name be changed to the Joint Section on Pediatric and Congenital Neurosurgery. I also suggest that a subsection meeting should be held around the time of the annual winter meeting to address the needs of these individuals. A prize or lectureship for work in this increasingly important field should be considered. My final recommendation to the Joint Section was that it should maintain and publish a registry of its members who accept or encourage adults in transition to be cared for in their practices.

**The American Society of Pediatric Neurological Surgeons**

The ASPN consists of physicians certified by the American Board of Pediatric Neurological Surgery. Most have had postresidency fellowships in pediatric neurosurgery. All have shown a long-standing commitment to a practice that is exclusively, or nearly exclusively, pediatric neurosurgery. A recent addition to the society’s vision statement reflects the recognition that the problems of pediatric neurological patients persist into adulthood (http://ASPNS.org/bylaws). The role of the ASPN is being debated. Active dialogue about this issue within the ASPN can fulfill a useful role. It is likely that any strategy would not work for all regions and situations. As various experiments such as the one discussed earlier, at the University of Utah/Primary Children’s Hospital are conducted, successes and failures will be discussed, and hybrid programs that are appropriate to the setting of each individual pediatric neurosurgical practice will be developed.

**The Healthcare System**

Help or change from the healthcare system is unlikely. Pediatric neurosurgery and congenital neurosurgery deal with a relatively small but fragile group of individuals, and reaching the attention of the government or healthcare insurers is difficult. The AAP and American Academy of Family Physicians are better positioned to advocate for young adults with SCNs. Some modest changes, however, might help to meet the challenge. It would be effective to define a set of SCNs clearly shown to benefit from coordinated, multidisciplinary care. The clearest example of such a condition is spina bifida. Creating carve-outs within Medicare and HMOs that recognize the need for and efficiency of coordinated care for these patients, and that reimburse appropriately for that coordination function, would be valuable first steps.

**Conclusions**

The transition of care from the practices of pediatric neurosurgeons to the community at large is a drama composed of many players. Each player is faced by significant challenges that differ greatly from setting to setting. This review attempts to define the cast of characters and the status of their efforts. However, transition of care for pediatric neurosurgical patients as a subset of those with SCNs remains a distressing challenge for affected individuals. As pediatric neurosurgeons, even if we cannot continue to care for the patients who graduate from our practices, we should be available as counselors to patients or their new healthcare team.

Patients must prepare for the transition and must fully understand their conditions, past treatments, outcomes, and current status. When patients 14 years or older move to a new area or are forced to change their healthcare setting, they should probably seek care in a setting that will still be available when they become adults.

**References**