

## Spina bifida transition care in India: strengths amidst challenges

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In India, adult neurosurgeons are required to care for children regularly because the concept of dedicated pediatric specialty care is not yet entirely established in the subcontinent. Likewise, pediatric neurosurgeons do not exclusively offer their services to the young, but they also provide care to adult patients with neurosurgical disorders. This creates a medical system where the transition between specialties is not often a formal and recognized aspect of neurosurgical care because most neurosurgeons provide care for patients of all ages. Additionally, there are very few teams geared toward caring for conditions in children that merit lifelong medical support, with spina bifida (SB) being one of them. Since there are no focused or structured pediatric programs on a large scale, developing a multidisciplinary clinic for adults becomes challenging. A pragmatic approach using technology-based education, supported by an organized system or a coordinator, may be a new strategy. A new system utilizing telemedicine and smartphones for established patients maybe an alternative option for SB children in India. During virtual video conferences, an established patient may benefit from multispecialty care and education toward a smooth transition that avoids significant issues with time, transportation, or financial constraints. Achieving a seamless transition among allied specialists from the pediatric to adult systems is a utopia. The current system in the subcontinent may be improved, with an opportunity to develop smooth transition care between coordinated specialists (who simultaneously treat children and adults). Learning from various global SB management styles, the Indian transition situation may offer another model in the near future.

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**L**IMITED surveillance studies in India suggest that the prevalence of spina bifida (SB) is approximately 40 to 50 per 10,000 births, much higher than the global rate.<sup>1</sup> It is unknown how many children survive to adulthood, but recent improvements in healthcare and education have resulted in a larger population of adults living with this condition.

Approximately 3500–4000 practicing neurosurgeons serve the more than 1.4 billion person population in the Indian subcontinent today.<sup>2</sup> About 450 million (20% of India's population) are younger than 18 years of age, and the specialty of pediatric neurosurgery is growing rapidly with the development of the Indian Society for Pediatric

Neurosurgery (IndSPN) with approximately 400 members.<sup>3,4</sup> However, most pediatric neurosurgeons do not exclusively treat the young but also provide care to adult patients with neurosurgical disorders, and adult neurosurgeons frequently care for children. A smooth transition of care for a patient from pediatric to adult care is essential and is presently needed for optimum healthcare in any part of the world; however, the concept of dedicated pediatric specialty care is not fully developed in the subcontinent.<sup>4–6</sup>

### Standards in Transition Medicine

The current SB transition standards and strategies for allied specialists are offered by the Spina Bifida Asso-

**ABBREVIATIONS** SB = spina bifida.

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**TABLE 1. Opportunities versus challenges of the current system**

Opportunities	Challenges	A Pragmatic Middle Path
Single physician management	1) No transition, 2) no multidisciplinary discussion, & 3) possible quality compromise	Adopting digital media & technology for virtual meetings & discussions
Improved patient/family rapport	1) Problem-specific expertise may be lacking & 2) communication/connectivity issues	Develop regional pediatric neurosurgery clinics supported by nodal centers/specialists
Patient & provider motivation for better options	Possible blind spots in the approach (missed opportunities)	Use individual & multidisciplinary approach based on needs & at intervals

ciation, American Academy of Pediatrics, Jacksonville Health and Transition Services (JaxHATS), the 6-step process toward effective SB transition, and others.<sup>7–11</sup> The methodologies have been effective at several centers of excellence, offering a path for many patients needing help with transition care. These centers have used various strategies and raised awareness with opportunities to learn from their experiences.<sup>8,12–14</sup>

## The Current Scenario and Challenges in the Indian Subcontinent

Similar to other entities in pediatric neurosurgery, SB transition is not formally organized in the Indian neurosurgical setting, with very few well-established and focused multidisciplinary clinics addressing this need in a unified fashion. Because there are no structured programs on a large scale, developing a multidisciplinary systems approach for adults becomes challenging. The official handoff from the pediatric age group to the adult specialists does not happen in a team setting and may occur individually or as needed.

Neurosurgeons care for all age groups because subspecialization or superspecialization is uncommon except in major cities and well-established medical centers. Also, the age-limited specialty hospitalization concept (dedicated pediatric institutions) has yet to be fully embraced, and therefore children are often admitted to facilities treating adults simultaneously. In most instances, the pediatric wing or hospital within a hospital setup is seen, and the same institution may continue to care for the SB patient well into adulthood. This contrasts with the West, where a specialty children's hospital concept exists, possibly with an age limit that forces the patient to seek other specialists or hospitals.<sup>2,9,12,15</sup>

## Optimism Amid Challenges

Transition is an almost daily occurrence in Indian neurosurgery, albeit with some exceptions. The same neurosurgeon typically cares for the individual from birth until adulthood and is often called upon to close the meningo-myelocele, insert a shunt for hydrocephalus if necessary (and treat any shunt-related issues), evaluate and release a tethered spinal cord, and treat Chiari malformation issues and other long-term problems. Similarly, the orthopedic surgeon may follow children for club feet/ambulation concerns and later maintain care to manage scoliosis or hip or other joint issues associated with SB care. Urological care may also be similarly followed into adulthood without a

definite need for transition from a pediatric to an adult specialist.

This ability to maintain care over decades and into adulthood is a good option and offers an opportunity for SB transition if the specialists can provide the full scope of complex care needed. Unfortunately, this model often lacks group discussions and the multidisciplinary team approach that benefits the established SB patient by limiting cost, travel, or confusion. Naturally, a healthy combined approach that properly and methodically manages complex issues is preferred, whereby the specialists render care as a team to address various problems simultaneously (Table 1).

Financing such initiatives is often challenging, especially with a lack of insurance coverage for a large, medically demanding population. Unless the government or hospitals invest in the initial infrastructure, such efforts may not yield the expected benefits. However, workforce and information technology are readily available, and a vast portion of the population is comfortable using smartphones; therefore, a digital technology-driven complementary effort toward SB transition may be pursued.<sup>16–19</sup>

After the initial upfront cost of development and personnel to maintain effective communication, such endeavors should yield positive results quickly. Financial support from government or academic programs and insurance schemes may augment these efforts. A coordinated multidisciplinary team could approach payors to support such efforts for effective SB transition (that could be modified for other disease entities). In addition, nongovernmental organizations may support the work with equipment or device donations and organize health awareness camps for transition patients to ensure equitable access to healthcare resources.

## A Pragmatic Way Forward—A Middle Path

A middle path or compromise situation may be a viable option toward integrated SB care for patients of all ages. Perhaps the Indian scenario can be molded to incorporate the already available neurosurgical care by a single provider team over the years by adding a few missing features. A coordinator with effective communication skills and technical capabilities with video conferencing can be helpful for established patients with SB transition needs. Physical meeting options may give way to less expensive alternatives and increase patient-provider interactions. A team-based approach with a triple focus of philosophy of education and financial and technical support may help address these issues.

Education using specialized tool kits may increase knowledge of potential issues and improve patient/family involvement regarding signs or symptoms of gradual deterioration. Software programs or smartphone applications may foster effective communication and engage and empower patients to seek appropriate, timely interventions from various specialists. A forum or national organization may improve comprehensive care for this population through advocacy, sharing of educational resources, and surveillance or data collection. The lack of a multidisciplinary clinic with an ill-defined endpoint or poorly executed strategy for transition could be overcome if various clinicians and subspecialists are comfortable with education for patients/providers and provide active involvement and timely interventions. In some situations, trained SB patients or families may be recruited as clinic coordinators or project leaders for such efforts.

Public awareness is necessary for such activities, with cinema or television being the best mass media options in India; educational advocacy-related materials and promotional advertisements can include transition to be disseminated widely. Learning from various global SB management experiences, the current SB transition situation may be improved with subsequent modifications to benefit patients with other chronic health conditions.

## Discussion

Amid the challenges of the healthcare system in the Indian subcontinent, a few opportunities for effective SB transition exist.<sup>16</sup> A patient could obtain near-total care throughout life using effective newer communication and social media tools and a prescribed program of specialist engagement. This new approach could develop a more effective and cost-saving method to maintain SB patient transition to healthcare by using the current advantages of the default single-point neurosurgical care or one hospital system for patients of all ages.<sup>2,7,9,20</sup>

Achieving a seamless transition among allied specialists in the pediatric and adult systems is a utopia. While the healthcare system in the subcontinent could be improved, there is an opportunity to enhance care during the transition period.

The healthcare system in India varies between the government and private sector, with significant variations from urban areas to the vastly rural population. At present, a system like the Western transition care model is challenging to visualize immediately in several low- and middle-income countries, including India. However, as more focused specialty care is offered, other team members may be gathered to develop a pragmatic approach that meets the patient's needs in one location by using a group delivery system. Once such a system is formed, the established patient can maintain care through periodic virtual visits, especially for transition-related issues.

## Conclusions

A concept for India is envisioned using education, technology, telemedicine, and smartphones to effectively improve communication and subspecialist involvement toward better SB management over the coming decades.

Government or nongovernmental organization support to develop hospital-based prototypes is needed to increase the infrastructure and personnel for effective communication. This model offers an exciting opportunity for continued care provided at the same hospital or clinician's office throughout life as an alternative to specialized pediatric and adult SB clinics with possible transition gaps. This may prove to be an effective model in the Indian subcontinent because the same provider or team sees pediatric and adult patients, enabling a system with seamless continuity of care.<sup>2</sup>

Addressing the challenges of transition management of SB patients in India requires a comprehensive approach involving healthcare policy reforms, community engagement, and advocacy efforts. By implementing targeted interventions and fostering collaboration among stakeholders, India can improve the quality of life and healthcare outcomes of individuals with SB during the transition from pediatric to adult care.

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## Disclosures

The authors report no conflict of interest concerning the materials or methods used in this study or the findings specified in this paper.

## Author Contributions

Conception and design: Pattisapu, Manda, Biradar, Mahapatra. Acquisition of data: Udayakumaran, Biradar, Kottakki. Analysis and interpretation of data: Mahapatra. Drafting the article: Pattisapu, Udayakumaran, Manda, Kedia, Mahapatra. Critically revising the article: Pattisapu, Udayakumaran, Kedia, Mahapatra. Reviewed submitted version of manuscript: Pattisapu, Udayakumaran, Manda, Biradar, Mahapatra. Approved the final version of the manuscript on behalf of all authors: Pattisapu. Administrative/technical/material support: Pattisapu, Biradar, Kottakki.

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