

Transition of Care From Pediatric to Adult Surgery

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In 2002, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians jointly published a seminal treatise on transitional care for the medically complex pediatric patient.¹ In it they laid the framework for providing comprehensive and coordinated care for the estimated 500 000 children with complex medical conditions entering adulthood annually. Subsequent research has highlighted the challenges with providing this type of transition, finding a decade later that 60% of teenagers with special needs and their families did not receive any structured transitional care planning.² The root causes of these failures are multiple, including lack of provider awareness or preparedness and a shortage of adult providers familiar with diseases such as cystic fibrosis, trisomy 21, and cerebral palsy. Patient and family reluctance in exchanging a protective, well-established, and nurturing pediatric environment for a more streamlined adult health care model may also contribute to this unease.

Pediatric surgery has been late to the table in discussing transition of care. Most congenital surgically corrected anomalies are now survivable. This scenario leaves a growing cohort of patients needing structured and anticipatory guidance on long-term care for their diseases such as esophageal atresia, congenital diaphragmatic hernia, functional and anatomic colonic obstructions, abdominal wall defects, and others. Recent research has sought to estimate the baseline and projected numbers of patients who may require formalized transition from pediatric to adult surgery,³ but we still lack understanding of the long-term needs of these patients who were operated on in infancy for a wide variety of congenital anomalies.

Why is this topic important? Are the long-term sequelae of congenital surgical anomalies not simply those of the generic postoperative patient? Are children who undergo operations in infancy substantially different in young adulthood from their healthy peers? Emerging data suggest that there are key differences which may result in adverse long-term outcomes if ongoing care and surveillance are ignored in adulthood. We are learning from follow-up studies in patients with Hirschsprung

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disease,⁴ congenital diaphragmatic hernia,⁵ esophageal atresia,⁶ and other diseases that as these patients enter adulthood, they are prone to experiencing the same “complications” seen in the medically complex population: declines in disease self-management, increased health-related complications, deterioration of health status, and emergence of secondary conditions.⁷ Herein lie the opportunities for preventive care education among both pediatric and adult providers and of our patients about these complex populations.

The benefits of a formal process of transition of care can be found in various specialty settings. The pediatric cardiology community, for example, has repeatedly demonstrated the advantages of coordination of care between pediatric and adult specialists, in both financial and health outcomes.⁸ Similarly, patients with spina bifida who have access to coordinated care clinics may have reduced rates of end-stage renal disease and lower extremity amputation.⁹ Solid-organ transplant patients following a transitional care plan seem to have lower rates of organ rejection than those with only episodic follow-up.¹⁰

One of the valuable sources of data on long-term care concerns are parent and patient advocacy groups. Some of the most prominent include CHERUBS for congenital diaphragmatic hernia (www.cherubs-cdh.org), EA|TEF for esophageal atresia (www.eatef.org), and The Pull-thru Network for a wide variety of anorectal functional and anatomic anomalies (www.pullthru-network.org). Working in conjunction with these groups, we are starting to acquire a more comprehensive and sophisticated understanding of the long-term needs of these patients, as well as the obstacles they face in receiving ongoing care. The barriers include a wide range of issues such as provider familiarity, insurance

coverage, and the psychosocial adaptation to the transition from pediatric to adult care models.

To overcome such barriers, close collaborations between pediatric surgical specialists, general pediatricians, and adult internists and surgeons are required to ensure a smooth and comprehensive transitional care process. From the pediatric surgery standpoint, there are at least 3 broad categories that need attention.¹¹ First, all stakeholders must better define the need. As a pediatric surgical community, we need to develop registries of patients undergoing surgical correction of congenital anomalies to better understand the numbers involved. Furthermore, a clearer understanding of the issues facing these children is integral and will allow us to create more uniform guidelines for what exactly comprises appropriate long-term care. Perhaps the best example within the pediatric surgical community is for congenital diaphragmatic hernia,¹² but more diseases need representation. Second, guidelines must be developed with input from all stakeholders to effect coherent transitional care plans in a timely fashion. This approach may take the form of “recommended long-term follow-up” plans. Third, we need to establish the value of formalizing the transition of care. The metrics of avoidance of costly emergency department visits and other forms of “catch-up” care must be demonstrated to justify reimbursement and further delineate the financial and societal impact of transitional care from pediatric to adult surgery. These costs are not only those related to surgical procedures and hospital admissions but include missed work and school productivity and the increased stressors on family life that accompany chronic disease.

For the primary care provider, integrated partnerships are needed to illuminate the issues at stake.

Pediatricians can help pediatric surgeons ensure that patients and families understand their surgical diagnoses and the procedures performed, in addition to what care is needed in the long run. Patients transitioning to adult providers should have access to their operative reports, imaging results, and follow-up plans. Providers and families also need to understand what local resources exist. In most urban settings, large academic hospitals can help bridge the gap between pediatric and adult surgical services. There may even be dedicated transitional care clinics and pediatric or adolescent medicine specialists interested in this topic. Access to such specialized programs may be limited in smaller cities and in rural areas. An important next step is to ensure that our colleagues can easily reach the primary surgeon involved, particularly if the patient or surgeon has relocated. Lastly and perhaps most importantly, the transitional care plan conversation should begin early. Young adulthood and official transition of care may begin at 18 years of age, but several societies recommend that the conversation begin as early as age 14 years to help ease the process and ensure success.

The diversity of congenital anomalies makes follow-up and transitional care challenging. Each patient has unique long-term care needs. The creation of a specific follow-up and transition of care plan needs to be individualized and is essential from the first postoperative visit and should be revisited in subsequent surgical visits with communication to the patient’s primary care providers regarding the progress of these plans. With the advent of the widespread use of the electronic medical record, communication with primary providers and surgeons will be facilitated and the transition of care plan can be better implemented. It is essential that as pediatric generalists

and specialists, we empower our “graduates” to mitigate long-term sequelae and thrive well into adulthood despite their congenital surgical conditions.

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