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Federal policy supporting improvements in transitioning from pediatric to adult surgery services



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ABSTRACT

For children with complex medical conditions that require ongoing surgical intervention, planning for the transition from pediatric to adult surgical care is essential. Services that support healthcare transition from specialty pediatric practices into adult practices are often inadequate, and the healthcare policy process has been slow to respond to the call to action by both professional and patient organizations. However, The Patient Protection and Affordable Care Act of 2010 (PPACA), arguably the most significant healthcare reform legislation since the enactment of Medicaid and Medicare in the mid-1960s, includes several provisions with direct influence on access to care and quality for adolescents transitioning to adult surgical care. We present a brief background on the rationale for improving surgical transition plans, the challenges of enacting the plans, and the relevance of PPACA in shaping health policy change around transition to adult services.

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Introduction

Many patients requiring major surgery during childhood will need ongoing chronic care well into their young adult years and beyond. This includes children who have both congenital and acquired surgical diseases that result in chronic disability and/or ongoing operative needs and multi-disciplinary surgical follow-up. Broadly speaking, this can range from children with chronic functional limitations due to congenital anatomic abnormalities that warrant specialized surgical care, to those with specific issues related to peri-operative management of inborn errors of metabolism or complex genetic syndromes that are more frequently encountered in the pediatric healthcare setting. Children born with Spina Bifida exemplify the former. These patients require ongoing multi-disciplinary surgical care into adulthood, including urologic, orthopedic, general, and neurosurgical follow-up. Although some of the specific procedures needed for these children are relatively common to both pediatric and adult surgical specialists, some procedures and their expected outcomes are

unique to pediatric practice. Furthermore, the often complex surgical history in these patients is challenging to communicate effectively across disparate medical systems that are typically involved in the transition from pediatric to adult care. In pediatric patients, parents often serve as common conduits of information between practitioners, but the role of the parent in the care of an adolescent or young adult patient is less clear, thereby pushing the burden of communication onto a potentially ill-prepared youth and the healthcare system.

For the most part, these patients are poorly served by United States healthcare systems and related transition policy.¹ Services that support healthcare transition into adult practices from specialty pediatric practices are inadequate. Specialty healthcare services for children and adolescents are largely regionalized in pediatric quaternary hospitals and related networks with few, if any, connections to adult community systems. Similarly, in most communities, behavioral health and social services are often oriented towards either the child or the adult with little overlap. On the policy side, public systems like Title V funding and Medicaid, the largest insurer of children in the U.S., traditionally have special programs or eligibility that limit their funding for patients at the age of majority. Such policies contribute to the traditional dramatic declines in health insurance coverage and

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access to care for young adults in the U.S. These limits are felt most severely by those with chronic and ongoing specialty conditions as they move from a generally supportive pediatric system into an adult system that expects patient autonomy.

Fortunately, relevant healthcare policy is rapidly changing, both with the passage of the Patient Protection and Affordable Care Act (PPACA) and more generally with market forces and related federal policy that promote value-based care. We review evidence on access to and effectiveness of care for patients with chronic surgical conditions transitioning from pediatric to adult care and examine changes in related health policy from the PPACA with other federal health policies that are likely to influence outcomes for high risk youths moving into the adult healthcare system.

Challenges in access to transition care

Adolescents with chronic surgical conditions requiring ongoing care into adulthood are infrequently studied in policy research, but instead, they are often lumped into the category of “special healthcare needs.” For most teens with special healthcare needs (SHCN), relatively high use of healthcare services continues from adolescence into adulthood, requiring a transition from pediatric to adult care settings and from parental care to self-care for health/disease management. Optimally, transition planning must be individualized to meet the varied developmental, health, and socioeconomic circumstances of teens with SHCN.² According to a consensus statement by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians–American Society of Internal Medicine, the goal of the transition process is to: “... maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue, uninterrupted as the individual moves from adolescence to adulthood.”³ Such transition support is of particular importance in children with medical complexity, including those with congenital conditions, multi-system issues, and technology dependence, who are often treated in the surgical setting and who have the highest levels of cost, utilization, and caregiver burden.^{4,5}

However, even given the general agreement on the importance of transition care, less than half of teens with special healthcare needs receive needed transition care and communication.⁵ Addressing this failure requires consideration of both patient and provider factors. On the provider side, professional organizations have offered several recommendations to promote successful transitions, including ensuring access to a medical home that provides care coordination and transition support; developing training programs for clinicians that improve transition skills; maintaining patient medical summaries and transition plans; using appropriate clinical guidelines; and supporting continuous insurance coverage through the transition from adolescence through adulthood.³ Of these recommendations, most research has focused on access to a medical home and availability of continuous insurance coverage.

The U.S. Department of Health and Human Services defines the medical home as a “cultivated partnership between the patient, family, and primary care provider in cooperation with specialists and support from the community.”⁶ The Agency for Healthcare Research and Quality⁷ defines the medical home as having five fundamental functions: (1) to be accountable for the majority of comprehensive healthcare provision; (2) to be patient-centered in its ability to incorporate and value individual attributes of the patient and how these affect medical care; (3) to be accountable for coordination of specialty care and primary care; (4) to be accessible and responsive to the patient continuously⁷; to demonstrate a commitment to quality improvement and

evidence-based practice.⁸ For most adolescents with ongoing surgical needs, a primary care clinician will act as the patient's medical home clinician, with the surgical specialist providing guidance and procedural expertise. On some occasions, the surgeon may take on the role of medical home but this should only happen when the vast majority of care is being delivered in the specialty area, this situation is likely to persist, and the surgeon is prepared to assist in care coordination and preventive care.

Access to a medical home has been proven to be a significant predictor of transition planning in children with special healthcare needs and has also been associated with better health status, patient-centeredness, timeliness, and family functioning.^{9–13} However, only 43% of children with SHCN receive comprehensive care within a medical home.¹

Besides lack of a medical home, breaks in insurance coverage are associated with gaps in healthcare and with poor transition planning.^{1,10,14,15} These gaps are associated with lower rates of access to primary preventative care services, increased emergency room use, and less prescription filling.^{16,17} Children with SHCN who experience lapses in coverage would also experience lapses in healthcare access and delivery that could worsen pre-existing conditions.

Even after controlling for access to a medical home and continuous health insurance, several patient characteristics remain significantly associated with transition planning. Transition planning is significantly worse for teens with SHCN who are male, non-Hispanic, African-American, whose family incomes fall between 100% and 400% of the federal poverty level, and whose condition affects their activities at least “somewhat.”¹ These disparities in transition planning for poor and minority youth may exacerbate health disparities in this population. Other psychosocial factors associated with transition include influence of peers and family members, desire to “fit in,” and developmental status.^{18,19} Developmental status is of particular importance when clinicians encourage personal responsibility for self-care. For example, research in teens with diabetes has shown that in pre-adolescence (aged 8–10 years), parents tend to dominate in disease management activities.²⁰ In early adolescence,^{11–15} roles begin to transition from parent to youth and by mid-adolescence, the teen becomes the dominant caregiver. However, this pattern of increased self-management does not necessarily link to positive health outcomes because teens often take on more responsibility than their maturity level can support.²⁰ As a result, the teen years are often a time of increased personal responsibility but decreased adherence to disease management regimens, sometimes resulting in increased mortality and morbidity.²¹

Transition support research in the adolescent surgical population is minimal and focused on a limited range of clinical populations; however, there is notable opportunity for improvement. For example, research in the kidney transplant population shows that poor transition services are associated with increased risk of graft loss in adolescents.²² Use of consensus guidelines developed to direct physicians in providing relevant transition counseling for kidney transplant patients²³ and use of specialized kidney transplant transition clinics show promise for reducing unnecessary medication changes and increasing patient satisfaction.²⁴ In the area of congenital heart disease, consensus guidelines from the American Heart Association stress that highly detailed individual information is essential for effective care transition. For example, adolescents with surgically corrected congenital heart disease oftentimes have residual cardiovascular physiologic derangements that demand an understanding of the reconstructed cardiac anatomy and its effects on physiology both at rest and during periods of acute illness in other organ systems.²⁵ Other surgical specialties including pediatric urology and anesthesia also document the importance and the paucity of structured transition

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