The Trials of Transition: How Well We Are Doing, and How We Can Do Better

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Transition of care from pediatric to adult-focused medical providers is an area that has received intense focus in recent years. This is particularly relevant for children and youth with special health care needs, defined as those patients "with chronic physical, developmental, behavioral, or emotional conditions who require health and related services of a type or amount beyond what is required by children generally."[1] It is even more daunting to plan transitions for the subset of children with medical complexity, who have "multiple significant chronic health problems that affect multiple organ systems and result in functional limitations, high health care need or utilization, and often the need for and use of medical technology."[2] The numbers of patients this involves is mind boggling: according to recent data, more than 10 million children overall from birth to aged 17 years have special health care needs, with approximately 17% of adolescents aged 12 to 17 years falling into this category.[3] Due to improvements in health care outcomes for children with underlying medical complexity, the vast majority of these patients will survive into adulthood, requiring increased levels of care and support.[4] For all of these reasons, the issue of transition will become even more pressing in the future as this population expands.

The transition of patients to adult medical providers remains less than optimal despite the strong consensus among all health care providers that a smooth transition from pediatric to adult-focused care is needed.[5,6] This is despite significant efforts to define and develop different transition strategies, including a *Clinical Report on Transition* published jointly by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians in 2011.[7] This transition is even more problematic for those patients with medical complexity, who are the most medically fragile and subject to serious adverse outcomes with poor transitions.[2]

In this issue of the *Journal of Graduate Medical Education*, Chung et al[8] describe a small study of a transition curriculum that utilized clinic experiences for residents in pediatrics, medicine-pediatrics, and internal medicine. The residents attended between 1 and 4 clinic sessions during an ambulatory rotation and were paired as pediatric-adult resident dyads to perform transition consultations. During this process, they were exposed to transition issues and teaching and were supervised by physicians who were knowledgeable about the transition process. The results of this intervention were assessed by pre- and postclinical surveys, with a majority of residents reporting positive experiences. This approach may have a positive impact on overcoming the "challenges health care providers experience establishing interdisciplinary partnerships."[8] There may also be benefit from simply exposing more residents to the concept of transition, and the challenges these patients face. The majority of residents, regardless of their specialty, receive little exposure or training regarding the principles and challenges of transition, so all attempts to introduce this important topic should be encouraged.

The barriers to successful transition are many, and include:

- Discomfort of adult providers in managing chronic diseases of childhood onset, with 1 study citing lack of familiarity with the literature and a lack of knowledge of certain disorders.[9]
- The need to continue to provide coordination of multiple specialists/services, with this coordination commonly assumed by pediatric medical homes or supported by agencies connected with pediatric medical homes. Coordination of services is often difficult for families to navigate on their own.
- Patients with cognitive disabilities may not be able to take ownership of their own health needs and may still be in the care of family caregivers in a dependent, rather than independent, relationship. This is usually a more comfortable and familiar scenario for the pediatrician than for the adult care provider. Also, many adult providers may experience discomfort when dealing directly with patients who have cognitive disabilities or challenging behaviors, including those along the

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autism spectrum, as adult providers may not have not received much exposure to this patient population during training.

- Behavioral challenges alone can affect a patient's ability to be independent and responsible for their own health care. These issues may be normal teenage behaviors, which can be outgrown over time, but need to be understood in the context of the patient's developmental stage of life. Alternatively, these behaviors may be more severe and disabling (including autism or mental health issues that are concomitant with intellectual disabilities). Behavioral issues, compounded by insufficient mental health supports, can complicate transition even for disorders such as diabetes, which adult providers are generally comfortable addressing.[10]
- Communication barriers may exist that prevent the adult provider from receiving all the information necessary to understand the patient's medical history and current needs. If an electronic health record has not been used for the patient's complex prior medical history, the transmission of pages upon pages of medical records may be daunting as well as incomplete.
- Institutional barriers may exist that prevent easy transition from a children's hospital to an adult facility. This may include lack of ability to perform procedures in cognitively disabled patients who require sedation and lack of schedulers to coordinate a complex array of appointments. Also, insurance issues can create institutional barriers: some institutions will not accept Medicaid or Medicare, which can affect whether a patient can be transitioned to the adult institution affiliated with the children's hospital at which care was previously delivered.
- Other insurance barriers exist that prevent continuity of coverage. For example, lapses in Medicaid or Supplemental Security Income can cause interruptions in care. Aging out of parental insurance after age 26 can also create interruptions in care.
- Lack of meaningful exposure to the complexities of transition at all levels of medical training as well as continuing medical education experiences creates an educational black hole and leads to management errors and breaks in continuity of care that can harm the health and well-being of patients.[11]

The topic of transition is a complex one and should be considered equally as important as understanding cardiac function, hematologic pathways, or renal anatomy and physiology.[12–14] Childhood to adult transition of care needs to be taught at multiple levels in medical training, from medical school through continuing medical education. Medical students should be introduced to the concepts of chronicity of illnesses that start in childhood and continue through adulthood. Pediatrics residents need to learn the steps in the transition process, so they can encourage independence and self-care in their patients capable of doing so, and educate the parents of their patients to expect transition to adult care as an inevitable process. For physicians who care for patients across their life span, such as medicine-pediatrics and family medicine physicians, learning about developmental issues during childhood that affect medical care and how medical as well as social problems evolve with age is critical.[6] During subspecialty training, physicians need to understand how disorders, whether cardiac, endocrine, or rheumatologic, present in childhood and evolve during adulthood.[6,12–14] Finally, practicing physicians, whose earlier training did not include curriculum and experiences covering the topic of transition, may need to participate in continuing medical education activities, as the number of children with medical complexities moving into adulthood continues to increase.[15] Transition will become a more successful process when providers at all levels are knowledgeable and are able to assist their patients in this complex but vitally important process.

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