Transition to Adult Health Care and the Need for a Pregnant Pause

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Early in fellowship, I met a 27-year-old woman experiencing severe systemic complications from sarcoidosis, first diagnosed when she was 10. For a decade she had been managed closely by a team of pediatric rheumatologists, with her disease in long-standing remission on anti-tumor necrosis factor therapy. At age 21, amid conversations about transferring soon to a local adult rheumatologist, the patient called her pediatric rheumatologists to report that she was pregnant. Her team responded by arranging for her to see an adult rheumatologist who specializes in rheumatology-related pregnancy care, and in so doing, transferred her to adult rheumatology care. Unfortunately, the patient never came to this appointment, and in one fell swoop, fell out of rheumatology care. I met this patient 6 years later when she was admitted to our hospital cachectic and in liver failure due to untreated sarcoidosis. Her postdischarge follow-up was arranged with me, then a combined adult and pediatric rheumatology fellow, in hopes that I could serve as a bridge across the pediatric-adult divide. Although she was due to see me just 2 weeks after discharge, the 27-year-old mother of 2 died the day before our appointment.

Many factors contributed to this young woman’s failed transfer, including low socioeconomic status, poor health literacy, mild intellectual disability, and underdeveloped self-advocacy skills. It is important to note, however, that these factors were all present when she was in pediatric care, during which time she had remained engaged in care with good disease control. What changed when she transferred to adult care? One answer, I believe, was the timing of her transfer.

Abrupt transfer due to pregnancy is common in pediatrics. Some pediatricians tell families they will keep patients “through college graduation or until one of the 3 P’s: prison, pregnancy, or partnering (marriage).” Many pediatric clinicians feel uncomfortable caring for pregnant patients, and there is a common belief that adult clinicians are more skilled at caring for these patients. However, recent data suggest that clinicians trained through internal medicine have similar discomfort with managing pregnant patients, particularly those with comorbidities.1

Pregnancy, especially unintended pregnancy in an adolescent or young adult, is an emotionally precarious time.2 It is, therefore, when a patient most needs continuity of care with a trusted provider and when loss of this provider can feel like abandonment. A young woman who decides to continue her pregnancy may prioritize obstetric care over routine chronic disease management; as such, pregnancy is a poor time to ask an expectant

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mother to invest in establishing with a new clinician. The physical, emotional, and financial strains of early motherhood, complicated by postpartum depression in one-third of young mothers, further interfere with a young adult’s ability to find or connect with a new clinician.

Instead, it is ideal for a patient to transfer during a time of medical and psychosocial stability and when the patient demonstrates crucial self-management skills, including the ability to independently take and refill medications, make appointments, arrange transportation, and communicate with the medical team. These skills, however, cannot be acquired overnight. Thus, when pregnancy, loss of insurance, acute hospitalization, or drug use is used as rationale for abrupt transfer, young adults are less likely to succeed in the adult system because of the abbreviated opportunity to prepare for the transfer, much like being asked to take off with a shortened runway. Furthermore, when transfer is precipitous and dictated by the medical team, patients often feel abandoned, as was the case with the previously discussed sarcoidosis patient, who intimated a sense of betrayal as the reason she never returned to see the doctors in the offending hospital system.

Given that it may take nearly a decade for a young adult to prepare for transfer, guidelines developed collaboratively by the American Academy of Pediatrics, the American Association of Family Practice, and the American College of Physicians advise clinicians to begin transition conversations when patients are 12 years old. As a patient approaches transfer age, the timing of transfer should be mutually agreed on by the patient, guardian(s), and the medical team. With a transfer date in mind, prepared young adults can view the transfer as a “graduation” from pediatrics, rather than as being “kicked out.” In addition, young adults and their parents appreciate pediatric teams providing a list of milestones toward which they should work, including the young adult patient being able to ask and answer questions independently during a doctor’s visit.

The process by which there is a gradual shift in responsibilities from parent(s) (or other caretakers) to the adolescent patient is embodied by the shared management model, which one of my favorite transition mentors colorfully captures this way: when a child is young, parents serve as the “chief executive officer” (CEO) of the child’s health care, and the child is an “entry-level” employee who does as told. Over time, an adolescent learns more skills and gets promoted to “manager,” whereas the parent CEO continues to supervise important tasks. The ultimate goal is for the young adult to become the CEO and for parents to retire to the board of trustees, offering occasional advice but leaving day-to-day management to the young adult patient.

Another critical factor in successful transfer is preparing young adults and their families for the experiential differences between pediatric-centered care and the world of adult-oriented medicine. We can set families up to succeed by helping them anticipate less hand-holding in adult clinics and greater expectations of patient responsibility. When cultural differences between pediatrics and internal medicine are discussed in advance, young adult patients often rise to the occasion; when they are not expressly warned of the added responsibilities, frequently they falter.

How, then, might things have gone differently for the young woman with sarcoidosis? Perhaps the transition would have been more successful if she had been coached in self-management skills, educated about the differences between pediatric care and adult medicine, transferred during a time of stability with ample warning rather than precipitously in response to pregnancy, and provided with posttransfer safety nets such as a transition coordinator managing a registry of transferred patients. The question, therefore, becomes how we can put systems in place to provide this support to young adults before, during, and after transfer?

There are multiple examples in the literature of how clinics, divisions, and health systems can improve transition and transfer. One of the most basic interventions is the development of a transition policy, which specifies the age and process for transfer and helps pediatric families prepare for what is to come. It also helps for a health care professional (sometimes a nurse or social worker) to meet with patients starting at age 12 to discuss, measure, and promote transition readiness with age-appropriate goals. In addition, care can be improved through educational interventions, transition coordinators (who function like a transplant coordinator, serving as a point of contact during and for a short while after transfer), transition clinics, and transfer registries.

What else can trainees do to help pediatric patients successfully transition and transfer? The first step is educating ourselves about transition best practices and asking that they be taught as part of the pediatrics core curriculum. We also can lead by example, taking the time to initiate transition conversations with our adolescent patients, assessing their transition readiness, and helping them to develop self-management skills.

Pediatricians take meticulous care of patients throughout childhood and adolescence, but transfer is not the finish line for young adults; instead,
we want young adults to "stick the landing," and successfully integrate into adult care. Through deliberate transition preparation and conscientious transfer care, we can help equip patients with the skills needed to succeed in adult health care beyond the date of transfer. After all, our ultimate goal as pediatricians is to help patients thrive beyond our office walls.6,8

ABBREVIATION
CEO: chief executive officer

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