Transition from Pediatric to Adult-Oriented Healthcare

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You know that children are growing up when they start asking questions that have answers.
—John J. Plomp

Learning Objectives:
1. Understand the distinction between transition and transfer of care
2. Appreciate the importance of planning for the transition from child- to adult-oriented health care
3. Become familiar with barriers to the transition of care
4. Outline one model for transition to an adult-oriented care system

Primary Reference:

CASE ONE:
One busy afternoon, you walk into your exam room to find Redd E. Tugo, a 21-year-old auto mechanic who has been your patient since he was born. He abruptly puts down the well-loved copy of “Where the Wild Things Are” that a previous patient had left in the room, and shoots you a nervous smile. “I’ve been thinking… I came to get checked out and get a refill on my asthma pump but… I was sitting in the waiting room with all of those coughing babies and was wondering if it’s still ok for me to be seeing you.”

1. Name some common ways that patients typically leave a pediatric practice. What is the upper age limit of pediatric care?

As described in a survey of pediatricians by Burke and colleagues, several common ways of leaving a practice are to age out (practice has specific policies regarding an age limit), to drop out (patient stops coming for care and is lost to follow-up), to be forced out (leaves for a reason not controlled by the patient or provider [e.g., loss of insurance coverage]), to move out (leaves practice to seek care from another provider), to hang out (continues coming to the practice after reaching the predetermined age limit), and to transfer out (defined for this purpose as a coordinated transition to an adult health care provider). In this study, the most common ways reported for patients without special health care needs to leave a practice were by ageing out (31%) or dropping out (21%), whereas patients with special health care needs were more commonly reported to hang out (29%) or age out (27%). A more recent study revealed that median age of transfer from a pediatric- to adult-focused provider was 21.8 years with a median gap of 20.5 months between last pediatric and first adult-focused office visit. Previously the AAP defined age 21 years as the upper limit of pediatrics, though in an updated 2017 Policy Statement, they note that this age cut-off is arbitrary, and that individualized decision-making based on the physical and psychological needs of the patient is more appropriate.

Moderators can invite members of the group to share stories about transition or finding adult-oriented care providers (in either their personal or professional lives).

2. What does it mean to transition from child-centered to adult-oriented care? How is “transition” different from “transfer” of care?

The bulk of the literature regarding the transition of care from the pediatrician to the adult internist has evolved around concerns specific to children and youth with special health care needs (CYSHCN). CYSHCN are defined by the US Maternal and Child Health Bureau as patients between the ages of birth and 17 years “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health or related services of a type or amount beyond that...
required by children generally.” While it is estimated that nearly 20% of US adolescents fall into this category, the concept of transition is applicable to all patients. The Society of Adolescent Medicine has outlined a commonly accepted definition of transition in the medical context: “the purposeful, planned movement of adolescents and young adults (with chronic physical and medical conditions) from child centered to adult-oriented health care systems.” Implied in this definition is the need for advance preparation of the patient, family, and provider, as well as the desirability of coordinated communication between providers of child and adult health-care.

In contrast, “transfer” is a discrete event in which a patient switches to an adult-focused provider. Ideally, transfer will occur as part of a coordinated transition process, though far more commonly, it occurs without any forethought given to the ways in which the care experience or provision might be different. Transfer of care, when it occurs outside of a coordinated transition process, is suboptimal for a variety of reasons. A transfer of care does not typically account for the ways in which prior communication between the child health provider and the adult provider might be beneficial to the patient, the family, and the medical team.

This uncoordinated transfer of care is, unfortunately, the default position. Given the stresses of a system in which there are too few primary care providers and those that are in practice have strict constraints on the amount of time that they can spend with each patient, it is the easy choice; it takes time and requires a concerted effort to establish open lines of communication between pediatric and adult teams in order to prepare patients for a transition between care providers.

After leaving their child-health providers, many young adults will receive no regular health care until an illness or other incident forces them to seek care in an emergency room or acute care clinic, often in a location distant from their previous medical home. The provision of optimal care under such circumstances largely depends on how knowledgeable patients are about their own medical histories and how comfortably they are able to both navigate the health care system and advocate for their own care.

While there is a physical component to the transfer of care, this is not necessarily the case with a care transition. There are primary care (e.g., a Med-Peds or Family Medicine practice) and subspecialty (e.g., adults with congenital heart disease clinics) models in which patients will continue to see the same set of providers, but the focus of their care will shift as patients become adults. This paradigm shift is a continuation of the process that is begun in pediatric offices as children progress through childhood and adolescence, but one which requires a specific skill set and deliberate attention to be successful.

While transfer of care can be a part of a transition process, attention should be paid to patient and family preparation, as well as the careful transfer of information between providers.

3. Why is transition of care important? What are the downsides of a patient remaining in a child-oriented health-care system indefinitely?

The importance of the transition process has been widely supported by position papers, opinion pieces, and qualitative studies that detail the impact of the transition process among CYSHCN with respect to patient/family satisfaction, self-esteem, and feelings of independence. Importantly, there is a growing body of evidence related to improved health outcomes and cost-effectiveness. A 2017 systematic review by Gabriel, et al. lists dozens of outcomes that have been shown to improve with implementation of structured transition interventions (e.g., adherence, quality of life, self-care skills, hospitalization rates), though an accepted best-practice for transition interventions has not been established.

Transition planning has broad implications for primary care. In a 2008 survey of Rhode Island pediatricians, 23% reported having patients 25 years of age and older in their practices, all of whom were CYSHCN. Many patients with chronic conditions have not been conditioned to think of themselves as growing into adulthood, by virtue of what they and their families may have been told about their condition since the time of diagnosis. Given the changes in life expectancy that have accompanied advancements in medical treatments for a number of chronic conditions (e.g., cystic fibrosis, congenital heart disease), many more CYSHCN are living well into adulthood and are faced with the accompanying needs for age-appropriate screening and care, such as routine gynecologic and obstetric...
care, sexual health, and mental health treatment. Pediatric providers are not necessarily trained or equipped to satisfy these needs. As succinctly stated by Callahan and colleagues “Adolescents with chronic illnesses must receive a clear, positive message that they, like their peers without illness, are expected to become adults, develop independence, and have productive futures.”

By remaining in a child-oriented system indefinitely, patients (both with and without chronic conditions) run the risk of not developing the confidence to take ownership of and advocate for their medical needs, which may ultimately impact their ability to seek appropriate care for acute problems or lead to the delayed diagnosis and treatment of age-related conditions. Successful healthcare in childhood can quickly unravel if adolescents and young adults are not equipped with the skills they need to maintain their health as adults.

CASE TWO:

Bea Prepared, a 13-year-old with sickle-cell disease, is a patient in your pediatric practice who comes in to see you for her annual physical. As you walk in the door and mentally begin to run through the typical adolescent issues that you want to cover today, you notice that Bea looks uncharacteristically anxious. When you ask what’s wrong, she asks, “Are you the kind of doctor who kicks kids out when they’re too old?” Her mother explains that Bea’s 22-year-old cousin had recently received a letter from his pediatrician’s office stating that he is too old to continue on in the practice and needs to find an adult doctor.

4. When should the transition process start?

In a series of joint position statements since 2002, the AAP, American Academy of Family Physicians (AAFP), and American College of Physicians (ACP) stress the need for a written health care transition plan by age 14 years for CYSHCN. The plan should include “what services need to be provided, who will provide them, and how they will be financed,” and must be updated regularly to ensure accuracy. In addition, a written portable medical summary should be prepared for all patients, which should include key medical information to assist with communication with all healthcare providers (current and future).

These same organizations recommend transition planning starting at age 12 regardless of a patient’s specific health care needs. Unfortunately, only limited progress has been realized since the 2002 statement. In the 2008 study of pediatricians in Rhode Island, only 13% of respondents had written policies about when/how to transition patients. Similarly, surveys of patients consistently reveal that transition-related discussions occur infrequently, even for those well into adolescence. For example, a 2018 analysis of the National Survey of Children’s Health revealed that only 17% of CYSHCN reported age-appropriate transition planning. A separate survey in 2017 of CYSHCN over 16 years of age found that only 4% of respondents reported having discussed a transition plan with their providers. In both of these studies, less than half of adolescents had spoken with the provider without a parent or guardian present.

5. Describe how you would guide Bea through transition. Should all patients transition according to the same timeline? What factors would you consider in determining the right “pace” of transition for a particular patient?

Moderators should encourage learners to frame answers around an established transition model. Many different models for care transition have been proposed and, while the specifics vary, the common thread is that there should be a gradual increase in education and responsibility which should start many years before the actual transfer.

The 2018 Clinical Report augments the 2011 report, calling attention to a related clinical framework developed by the Center for Health Care Transition Improvement called the “Six Core Elements of Health Care Transition” which aligns with the 2011 transition algorithm, and which emphasizes that transition does not end at time of transfer because it can take an additional few years for young adults to successfully integrate into an adult care model. The elements do not represent a pure chronologic sequence of events, but rather a process in which components from multiple elements occur
simultaneously. The six elements as well as the specific tasks involved in the process are outlined in detail on the “Got Transition” website (see Resources).

1. Transition Policy - The concept of transition should be introduced to the family early in childhood, during which the provider must educate and counsel families regarding long-term planning. What medical care might be necessary in young adulthood and beyond? Where might appropriate services be found (community vs. academic center)? Families should envision a time when children will become more independent and able to manage their own healthcare needs. This should be specifically addressed by age 12.

2. Transition Tracking and Monitoring - Ideally, flow sheets and registries are utilized to track a patient through the transition process.

3. Transition Readiness - Starting at age 14, transition “readiness checklists” should be used serially to monitor a patient’s progress over time (see Resources section). The Transition Readiness Assessment Questionnaire (TRAQ), reproduced in Figure 1 of the primary reference is one such instrument. Through use of these checklists, providers can prioritize goals jointly with transitioning youth and their families.

4. Transition Planning - As children mature developmentally, specific attention must be given to engaging them in their care. The healthcare team must ensure that children understand their diagnoses and medical histories, including basic pathophysiology of disease, rationale behind treatments being used, and options for future therapy. Patients should be taught about signs or symptoms that would require medical attention. Such conversations must be repeated over time, adding in layers of sophistication and knowledge as children mature. Upon reaching adolescence, education about navigating the healthcare system should occur (e.g., carry your insurance card and portable care summary, frequency of follow-up, how to access routine care and emergency care, how to obtain refills). This should be done as early as is developmentally appropriate, but should be specifically addressed during visits between the ages of 14-18.

5. Transfer to Adult Approach to Care - A flexible policy regarding timing of transfer to an adult-care system should be in place and discussed early on as part of the transition process. Ideally, transfer will occur after many years of transition planning, during which time patients have gained the necessary knowledge and skills to care for themselves independently. Providers should keep in mind that underlying illness often impacts normal developmental trajectories when deciding on timing of graded increases in responsibility for each individual patient. Importantly, transfer during periods of acute crisis or terminal illness should be avoided. The care team should create a transfer package for the adult team that contains a medical summary along with other relevant documents. The AAP/AAFP/ACP support transfer between the ages of 18 and 21 in most circumstances.

6. Transfer Completion - After transfer of care, the pediatric team can follow-up (usually by phone) with the patient and adult care team to ensure that care needs are being met, answer questions that may have come up since last contact, and seek feedback on the transition process. Many patients will require ongoing support and guidance related to navigating adult health care during the first few years after transfer.

One could imagine using this model to guide our patient, Bea, through her transition process:

At the time of Bea’s diagnosis with sickle cell, the provider would talk with the parents about the expected course of her condition, educate the family about her expected lifespan and advances that have been made in treatment, and emphasize the fact that Bea may have a relatively normal childhood and young adulthood. As Bea is able to join the conversation, the provider should engage her and her family around their respective goals and dreams for her future as an independent adult. This should be specifically revisited when Bea is 12 or 13 years old. As Bea grows older, the provider would give her more responsibility with regard to managing and understanding her condition (e.g., asking Bea to develop a sense of her typical pain crises and triggers), and enlist the family in reinforcing this message. The provider may assign Bea the “homework” of bringing a certain number of questions about her health and her body to each visit, and address Bea first during visits with her family, ultimately taking a portion of the visit to talk with Bea alone. Once Bea is able to handle basic responsibilities, she should work with her provider to develop those skills that will allow her to become a successful advocate for her own care. One example would be for Bea to develop and familiarize herself with a portable medical summary, detailing key components of her history (e.g., number of
episodes of acute chest syndrome, baseline hemoglobin level, the date of her last hospitalization), contact information for any subspecialists, insurance information, medication lists, and emergency contact numbers. Other examples could include working with Bea to develop and write a detailed transition plan, asking Bea to identify and meet with an adult-oriented primary care provider, and discussing with Bea the importance of making appointments for regular health checkups (including gynecologic care), as appropriate.

A number of educational modules are available including practical guides for patients, parents/caregivers, and health care providers, sample portable medical record forms, and questionnaires designed to assess those core competencies that are necessary for patients to become independent in managing their own health care. Sample material can be found in the Resources section. *Moderators should note how these models are also applicable to children without chronic illnesses.*

6. **What are some barriers to making a “good” transition?**

Despite acceptance of the importance of the transition process by patients and families, and the support of professional organizations, many barriers to successful transition exist. Several barriers have been described including:

- Lack of preparation before transfer from pediatric- to adult-oriented providers where age is used as the trigger for transition (as opposed to an assessment of maturity or independence);
- Shortage of adult-oriented providers with expertise in pediatric-onset chronic conditions;
- Lack of communication between pediatric- and adult-oriented providers;
- Difficulty adjusting to a change in the emphasis of care from a family-centered model to one in which patients are expected to take responsibility for their own health issues;
- Lack of insurance coverage or different qualification requirements for coverage of adult-oriented care (in most states, the requirements to qualify for public health insurance are less liberal for adults than for children); and
- Lack of financial reimbursement for providers for time spent in working through transition-related issues and coordinating care among multiple subspecialists. Table 2 in Mahan, et al. lists some billing options, and more comprehensive guides have been published by the Got Transition/Center for Health Care Transition Improvement project, together with the AAP (see Resources).

The amount of individual and financial commitment required to incorporating principles of transition into the US healthcare and medical training systems pose barriers to their implementation, though the Patient Protection and Affordable Care Act contains some provisions which benefit CYSHCN (e.g., creation of integrated provider networks, support for incorporating “medical home” concepts into residency training, extending dependent insurance coverage through age 26, eliminating pre-existing condition exclusions and lifetime insurance caps).

A team-based care model can also help overcome some of these barriers. For example, transition coordination by nurses and social workers can improve implementation of a transition model and drive local quality improvement efforts.

**Additional References:**


Resources:
5. Transition resources for patients, families, and providers from Connecticut DPH. http://www.ct.gov/dph/cwp/view.asp?a=31386q=432684
7. A more extensive list of transition-related resources appears at the end of the AAP/AAFP/ACP 2011 Clinical Report. http://pediatrics.aappublications.org/content/128/1/182.full.pdf+html