Due to advances in modern health care, a child born today with a chronic illness such as cystic fibrosis, spina bifida, or sickle cell anemia has a 90% chance of living into adulthood. These young adults with special health care needs (YASHCN) and their families will need to navigate the transition from pediatric to adult-oriented health care. In addition, the internists receiving these patients must also be prepared to take on patients with unfamiliar and uncommon chronic health conditions that are complicated by the social and emotional development of these young patients.

Ideally, transition should occur as a process that involves multiple steps to prepare the YASHCN and not just a simple transfer from a pediatrician to an internist. The 2005-2006 National Survey of Children with Special Health Care Needs defined appropriate transition services as: 1) planning the shift to an adult provider to address future health care needs, 2) encouraging the development of self-management skills, and 3) providing information on insurance maintenance. In addition, the 2002 consensus statement on transition states that the “knowledge and skills needed to provide developmentally appropriate transition services to YASHCN should be part of the training and certification requirement for primary care residents and physicians in practice.” What the consensus statement doesn’t specify is what these educational requirements are and when residents should receive this training. Part of this transition process is the domain of the adult medicine-trained physician, but it is not clear what educational processes have, or should be, put in place.

There is currently no consensus as to when and how training residents regarding transition should be done. There have been a few published surveys trying to elicit educational needs. One survey of eight primary care training programs in South Carolina elicited residents’ preferences for a curriculum on health care transition. In this survey, 61% of residents had at least monthly encounters with patients at or near the age of transition. Regarding preferences for types of training in transitions, 79% wanted clinical experience, 60% wanted case-based discussions, and 57% wanted a lecture format. Only 10% of residents preferred a web-based modality. The majority of residents (79%) preferred a continuous curriculum throughout residency as opposed to a particular year of training. In addition, 84% of pediatric residents were open to the idea of rotations with patients outside their scope of training (i.e. adult patients) compared to only 42% of internal medicine (IM) residents. Topics of greatest need/interest included: medical knowledge of pediatric illness persisting into adulthood (77%), identifying resources for YASHCN (57%), discussing end-of-life issues with young patients and families (66%), and caring for adult patients reliant on caretakers (53%).

A second single-institution survey of IM and pediatric residents revealed that both groups of residents felt that transition should occur at a mean age of 18. However, only 13% of IM residents compared to 78% of pediatric residents had participated in an educational session regarding transition. IM residents were significantly more uncomfortable treating childhood-onset illnesses with the exception of asthma. Discomfort with neuro-developmental disorders, such as autism spectrum disorders, was particularly striking. There was less of a difference in the level of comfort in treating chronic disease in the outpatient setting between pediatrics and IM residents. However, IM residents did not feel they would be likely to care for patients with autism, cerebral palsy, or spina bifida after completing residency. In response to this discomfort caring for YASHCN, this particular institution created a curriculum to address transition needs involving disease-specific transition presentations, medical school advocacy seminars, and a training program for ancillary health care professionals.

At present, several barriers explain the hesitancy to transition the YASHCN from the pediatric to the adult medical home, including:

1. Pediatric care is more family focused, with parents taking charge of most decision making;
2. Families and patients may be reluctant to let go of an established relationship with a trusted physician;
3. Funding and access to key staff are limited;
4. Transportation, legal services, social services, and vocational services are all needed in the course of care; and
5. Internists may feel uncomfortable treating diseases that are unfamiliar to them.

Internists are generally the group of providers most often charged with caring for patients with chronic medical illnesses. The main difficulty in caring for YASHCN is recognizing the intellectual and emotional challenges of these patients. Although internists have some familiarity with shared decision making in the care of elderly or demented patients, they may struggle to recognize these barriers in younger patients. Many YASHCN have intellectual and...
or developmental issues due to the underlying disease (sickle cell, autism) or sequelae of disease treatment (cancer, transplant). They often have lower levels of educational attainment and health literacy due to their chronic disease. Internists have to be prepared to recognize these limitations and adjust their patterns of care. YASHCN may not yet have developed self-management skills and often have to develop these skills while transitioning to the adult provider. These young adults may need help in developing communication skills, advocating for themselves, and making decisions.

YASHCN often have legal and insurance barriers that first manifest themselves at the age of transition. Current changes in healthcare law now allow these young adults to remain on parental insurance until age 26, but adult care providers will need to be prepared to help these patients retain medical coverage. Maintaining insurance status is often critical to achieving optimal health but made difficult by the fact that many YASHCN are not employed and are reliant on public insurance (Medicaid and Medicare). Eligibility requirements become more stringent for adults and make this an additional hurdle interns must become familiar with to aid these patients. Some YASHCN will also need to have legal clarification of their ability to consent for both medical and legal decisions. Although this is ideally done before age 21, it is often neglected and may need to be addressed by the adult health care provider.

One survey of adult sub-specialists attempted to identify the specific knowledge gaps and barriers to accepting YASHCN into their practices. A 2008 survey of adult gastroenterologists reported that 55% of young adults with inflammatory bowel disease had deficits in knowledge of their own medical history and that 69% did not know the medications they were taking. Additionally, 51% of adult providers received an inadequate medical history from the pediatric provider. This survey also indicated that adult sub-specialty providers were less concerned about the YASHCN ability to identify previous providers (19%) or attend office visits by themselves (15%). Respondents believed that knowledge of adolescent medical and developmental issues was important, but only 46% felt competent addressing developmental concerns. Surprisingly, physicians in practice for less than five years reported more problems with transition issues than their peers further out from training.

These studies highlight the importance of the pediatrician readying the YASHCN for the transition by educating the patient regarding the chronic condition and assessing legal and medical capacity. Adult providers and families were less concerned regarding the initial need for family- vs. individual-centered care and decision making. All studies recognized the need for ongoing medical education of the adult providers regarding the needs of these patients as they transition to adult care. One of the responses to this need is an ongoing series published by the American Academy of Pediatrics (AAP) that includes articles on the transition of patients with specific chronic disease (e.g. sickle cell, cystic fibrosis, diabetes mellitus, and abuse) to internists. The next challenge will be getting this knowledge into the adult/IM literature. Training curricula must be developed for students, residents, and fellows to provide primary and specialty care for this growing group of patients.

References
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