COMMENTARY: PART I

Lost in Transition: Young Adults with Special Health Care Needs
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Young adults with special health care needs (YASHCN) represent a growing population of patients that are currently or will soon be receiving care in adult-oriented health care systems. YASHCN include individuals with a wide range of chronic physical and mental health conditions as well as those with developmental and mental disabilities. As a group, they often face unique challenges in their transition to adulthood in both health care and non-health care domains. In this issue of SGIM Forum, articles will highlight many of these challenges and offer insight to addressing many of the obstacles to achieving effective, appropriate long-term care for these individuals.

Advances in medicine over the last several decades have resulted in a significant increase in the number of pediatric patients with chronic medical conditions who survive to adulthood. For example, whereas the median age of survival among individuals with sickle cell disease was estimated to be 14.3 years in 1973, more recent data have demonstrated that 85% of such patients now survive to 18 years of age. Today, a comparable proportion of patients born with cardiovascular anomalies are expected to reach adulthood. Likewise, the median predicted age of survival for patients with cystic fibrosis has risen from 26 in 1985 to 37.4 in 2007. Similar trends of improved survival have been seen for pediatric and adolescent patients diagnosed with malignancies and perinatally acquired HIV infection. Recent estimates suggest that the prevalence rate of mental disabilities in the non-institutionalized US population is about 7.8 people per thousand while the prevalence rate for developmental disabilities is about 11.3 people per thousand. That said, approximately 1 million individuals with mental challenges and developmental disabilities are likely to be transitioning to adult medicine over the next five years. Additionally, there are 2.4 million non-institutionalized adults age 18 to 26 with serious mental illness.

Despite the large numbers of YASHCN needing to transition to adult medicine, data suggest that the organization of our current health care system and its adult-oriented medical centers are poorly prepared to meet this demand. A recent survey of 1,500 non-elderly adults with disabilities reported that one half had to postpone care or had difficulty in acquiring needed medications or medical equipment. It has also been shown that, among young adults with mental health conditions, inpatient admissions increase during the age of transition, perhaps suggesting limited access to ambulatory services. Additionally, observational studies have suggested worsening glycemic control in patients with type I diabetes mellitus, increased incidence of graft failure in solid organ transplant recipients, and increased rates of hospitalization among cystic fibrosis patients during the transition period. There are several factors that likely contribute to these adverse health outcomes. Surveys of both pediatric and adult providers cite poor communication as a significant barrier to the transition process. Internists also express concern about having insufficient training and inadequate support to appropriately care for YASHCN. Further, lapses in health insurance coverage often limit a successful transition, with many YASHCN becoming uninsured at age 19 because they have aged out of their parents’ insurance plan or because they no longer qualify for public insurance coverage.

In addition to challenges in health care transitions, the needs of YASHCN in non-health care domains are also not being adequately addressed. Data suggest that approximately 20% of individuals with disabilities and more than one third of non-institutionalized adolescents with mental illness do not complete high school—more than twice the rate of their peers. Similarly, it is estimated that 35% of people with disabilities are employed compared to 78% of those without disabilities. Consistent with these findings, individuals with disabilities are much more likely than their peers to worry about not being able to live independently or being a burden to their families. YASHCN have also reported that they feel as if they are perceived as being asexual and often suffer a negative body image and low self-esteem. Perhaps not surprisingly, individuals with disabilities report much lower rates of life satisfaction. In light of the many difficulties faced by YASHCN as they transition to adulthood, it is imperative that adult-oriented health care systems institute strategies to better support this process. Enhancing collaboration between transferring pediatric providers and receiving adult providers is necessary to ensure that these patients receive comprehensive, coordinated care as they transition to adult medicine. This will require investments in the training and development of pediatric providers to assist with transitioning patients to adult medicine as well as investments in planning, organization, and facilitation of care transitions. In addition, the integration of mental health and primary care services is needed to improve the quality of care for these patients. Finally, the development of new models of care that can bridge the gaps between pediatric and adult care will be necessary in order to ensure that YASHCN receive the care they need as they transition to adulthood.
providers would be a key initial step. By improving bi-directional communication over the course of the transition process, providers might better assure that the goals of the YASHCN are met in all domains of their lives. Further, providing adult providers with a heightened understanding of available resources to support YASHCN, including educational, vocational, and independent living opportunities, will likely lead to better health outcomes and patient satisfaction while simultaneously alleviating provider anxiety. A greater emphasis on the transition process and the long-term care of YASHCN in medical school and resident training curricula should be considered an important part of the education of future adult providers. Lastly, interventions that help to eliminate gaps in health insurance coverage as YASHCN transfer to adult-oriented care centers would certainly have a positive impact.

References