The Transition Journey: Time to Systematically Address Transition Planning to Adult Health Care

Megumi J. Okumura, MD, MAS

Since the 1970s, researchers and clinicians have documented the difficulties and subsequent poor health outcomes experienced by youth with special health care needs (YSHCN) during the transition from pediatric to adult health care. In 2002, *Pediatrics* published the American Academy of Pediatrics recommendation of improving the transition of care for YSHCN from pediatric- to adult-focused care[1] as a step toward meeting the goals of *Healthy People 2010*. The recommendations specified that all YSHCN have appropriate transition and transfer planning through education and generation of a transfer summary. The goal was to ensure "high-quality, developmentally appropriate health care services are available in an uninterrupted manner as the person moves from adolescence" to "maximize lifelong functioning and well-being for all youth"[2] regardless of whether the individual has a special health care need. Sixteen years later, in this issue of *Pediatrics*, Lebrun-Harris et al[3] visit the follow-up question: What is the current state of health care transition planning in the United States? Perhaps, after over 40 years of discussing improvements in transition, the better question is: Are we there yet?

The 2016 data revealed that 41% of YSHCN replied "yes" to the question of whether they had discussed the shift to adult care; this is largely unchanged from 2010.[4] It seems that our pendulum has not moved at all despite the increasing body of literature citing the poor quality of care that is being experienced by YSHCN and the increasing focus on pediatric programs to improve the transition process in specialty and primary care clinics. If we look at data from the current study, only 17% of YSHCN are meeting the composite metric of transition planning.

We need to be mindful that the metrics and quality indicators used to evaluate transition outcomes are still being developed. Measures, such as those developed by the Maternal Child Health Bureau,[5] do not fully capture the complexity involved with transition and transfer. There are numerous domains that need to be addressed; these include ensuring competence in disease management and developing life skills in and out of the home as well as in the medical environment.[6] The gold standard for ideal transition outcomes has been widely discussed and is still up for debate.[7] For example, successful scheduling with an adult provider may not be the ultimate goal; rather, having a job and being able to manage one's own disease may be of greater value for some patients. The measures noted in this article are important components in the transition process; however, as the authors note, simply achieving these measures does not guarantee a "successful" transition and transfer. Just the same, we have to start somewhere, and preparing youth for adulthood is arguably our responsibility as health care providers.

The current article shows us that we have a long way to go before we reach

Departments of Pediatrics and Internal Medicine, University of California, San Francisco, San Francisco, California

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Address correspondence to Megumi J. Okumura, MD, MAS, Division of General Pediatrics, University of California, San Francisco, 3333 California St STE 245, San Francisco, CA 94118. E-mail: megumi.okumura@ucsf.edu

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the goal of preparing all YSHCN in transition and ultimate transfer to adult health care. Until our health system supports pediatric providers in offering adequate transition planning, it will be difficult to expect any uptick in these measures. In addition, we still need to understand why some adolescents fail in their transition and transfer and how to develop the appropriate interventions to improve health outcomes for these patients. We continue to require the research and clinical intervention studies that will develop the appropriate quality indicators for transitions of care. We cannot lose focus on other critical aspects of transitioning, such as addressing family support, youth mental health, and navigating a fragmented health system. The problems of transitions of care are the proverbial "canary in the cave" that indicates greater problems in our current health care system. The often-consolidated care we find in the children's hospitals has simply shielded youth from the realities of a beleaguered health care system with which many adults with chronic disease are currently struggling.

Fortunately, our medical societies, funders, and many of our health systems are trying to improve the transition and transfer process for our adolescents and young adults. The adult system of care has numerous quality improvement initiatives to address chronic illness management and care. We must continue to improve not only our transition processes but also the overall care systems in which these adolescents and young adults reside. Ensuring that all persons have a medical home with continuity of care, access to appropriate therapies, mental health services, and social supports is critical in promoting high-quality medical care. By having such systems in place, we can then provide the needed supports for transition and transfer for our patients. This, in turn, will benefit all individuals in our health care system. When we have all these components in place to meet the needs of our patients, we may be closer to being "there."

ABBREVIATION

YSHCN: youth with special health care needs

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