

Transitioning Kids With Chronic Diseases Is Tough

BY KATE JOHNSON
Montreal Bureau

TORONTO — Time and reimbursement are among the biggest concerns for physicians involved in helping patients with childhood-onset chronic diseases make the transition from pediatric to adult care, according to Dr. Megumi Okumura of the University of California, San Francisco.

“Many of these diseases are unfamiliar to adult providers because it is only recently that patients ... have started surviving into adulthood,” she said at the annual meeting of the Pediatric Academic Societies. “In fact, many of these patients are largely cared for in the pediatric setting, even as adults.”

Surprisingly, however, it is not disease-specific knowledge and training that are the overriding concerns for pediatricians or in-

ternists as they help patients make the transition to adult care, she said. Instead, physicians cite lack of time, reimbursement, and psychiatric resources as their main obstacles.

“These patients require significant chronic-illness management and coordination with specialty

Lack of psychiatric support was identified by pediatricians as the main obstacle, followed by lack of time and lack of reimbursement.

care beyond what is typically done in the primary care setting,” she said. “A lot of the office infrastructure isn’t there to help physicians coordinate this complex care. It doesn’t really matter what the disease is, there just is not time in a primary care practice to [address] their needs,” she said in an interview.

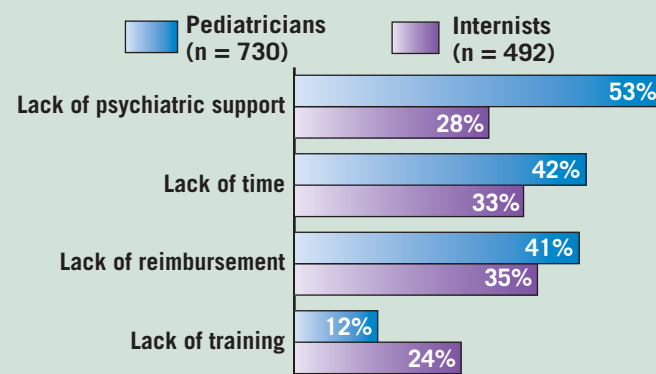
Dr. Okumura presented her

national survey of 492 internists and 730 pediatricians, in which she asked about disease-specific resources as well as barriers to overall care delivery for young adults with sickle cell disease, cystic fibrosis, and complex congenital heart disease.

She found that both pediatricians and internists reported reasonable access to general resources such as physical and occupational therapy, as well as disease-specific resources such as hematology, pulmonology, and cystic fibrosis or sickle cell disease centers.

Lack of psychiatric support was identified by pediatricians as the main obstacle (53%), followed by lack of time (42%), and lack of reimbursement (41%). For internists, reimbursement concerns were at the top of the list (35%), followed by time (33%), and lack of psychiatric support (28%).

Barriers Identified for Young Adults With Childhood-Onset Chronic Diseases



Note: Based on a national survey about barriers to treating sickle cell disease, cystic fibrosis, and complex congenital heart disease. Source: Dr. Okumura

When asked about factors associated with their ability to provide high-quality care for patients, both pediatricians and internists cited office structure, Dr. Okumura said.

“Internal practice-based barriers

are more significant to clinicians than lack of external disease-specific resources or training,” she said, noting that lack of training was called a concern by 24% of internists and 12% of pediatricians.

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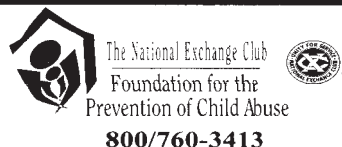
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