

# Most generalists reluctant to provide primary care for young adults with chronic illness

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The majority of general internists and pediatricians in the United States are not comfortable serving as primary care providers for young adults with complex chronic illnesses that originate during childhood, according to findings from a new national survey.

The survey, conducted by researchers at the University of California, San Francisco and the University of Michigan, examined a random sample of internists and pediatricians to assess their comfort levels in treating young adult patients with cystic fibrosis (CF) and sickle cell disease (SCD) – two hereditary diseases that involve single gene mutations.

"My interest is in how to improve the quality of care for youth and young adults with childhood onset chronic diseases," said Megumi Okumura, MD, lead author of the paper who is an assistant professor in pediatrics at UCSF and treats patients at UCSF Children's Hospital. "These individuals are a unique bunch, because they are born with their diseases, and the health care services they receive as children are not necessarily matched in the adult health care setting."

Survey findings showed that only 15 percent of the general internists said they would be comfortable providing primary care to young adult CF patients, while 32 percent reported being comfortable providing care for those with SCD. Among the pediatricians surveyed, 38 percent said they would be comfortable serving as the primary care provider for CF patients, while 35 percent said the same for treating patients with SCD.

Both the internists and pediatricians reported that they would be more comfortable treating young adults with common diseases, such as asthma and hypertension, than treating patients with a history of CF and SCD.

Findings from the survey are currently available online at <http://www.springerlink.com/content/rj738l32700m35k1/> and will be published in the October issue of the "*Journal of General Internal Medicine*."

Advances in medical treatments have significantly extended the life expectancies for patients with chronic conditions such as CF and SCD, which had previously been fatal in early childhood, according to Okumura. Consequently, the prevalence of chronic illness among young adults has also significantly increased. Up to 30 percent of children today report having some sort of chronic condition, she said.

"The technology has been remarkable in keeping people alive. What we are so lacking in is how to keep taking care of them and give them the health services they need to have productive lives," Okumura added.

To effectively meet the needs of the growing adult population living with chronic conditions, experts now recommend that young adults begin transitioning from child-focused to adult-oriented primary health care when they are 14 years old. However, according to Okumura, the study findings indicate that generalists are not yet prepared to handle the wave of individuals with chronic conditions needing primary care, and this could have a negative impact on the patients' care overall.

"Generalists are the primary caretaker and safety-net for people with chronic disease. They are there to help any patient who walks through their door, and it's up to them to figure out which subspecialist to recommend and what other resources are necessary for their healthcare," Okumura said. "I consider them the foundation of health care, and when

that falls apart the entire health system becomes fragmented and it becomes difficult to provide high quality care."

A total of 1288 physicians responded to the survey, which was issued by mail to equal numbers of general internists and general pediatricians between October 2005 and March 2006. Of those who responded, 537 were internists and 751 were pediatricians.

Each physician randomly received one of two survey versions – one containing a clinical vignette involving a patient with CF, or a second describing a nearly identical patient with SCD. After reading the vignettes, the physicians were asked to rate how comfortable they would be serving as the patient's primary care provider.

Survey participants also responded to questions about how certain barriers, such as a lack of training or lack of time during office visits, might limit their ability to provide high quality primary care for young adults with chronic illness. The findings indicated that internists were more likely than pediatricians to say that insufficient training limited their ability to care for these patients, while pediatricians were more likely to report barriers due to insufficient time during office visits.

Okumura said future studies should examine the factors that are directly affecting the quality of care for young adults with chronic illnesses, and how those factors impact patient outcomes.

Source: University of California - San Francisco

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