Special Needs Teens Face Rocky Path to Adult Care

BY SHARON WORCESTER
Southeast Bureau

BOSTON — If those practicing in Rhode Island are any indication, primary care pediatricians have some work to do when it comes to incorporating guidelines provided by the American Academy of Pediatrics for the transition and transfer of adolescents with special needs to adult health care.

A survey of 103 pediatricians, representing 80% of pediatric primary care practices in the state, showed that 87% have no formal policy for transferring adolescent patients with special needs to adult health care. This suggests the specialty is in the early stages of adopting the guidelines, according to Dr. Robert T. Burke, who presented the findings in a poster at the annual meeting of the American Academy for Cerebral Palsy and Developmental Medicine.

A consensus statement published jointly in 2002 by the AAP, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine (now the American College of Physicians) on such transition and transfer of care was approved as policy by the boards of these organizations.

The statement aimed to "ensure that by the year 2010 all physicians who provide primary or subspecialty care to young people with special health care needs (1) understand the rational for transition from child-oriented to adult-oriented health care; (2) have the knowledge and skills to facilitate that process; and (3) know if, how, and when transfer of care is indicated" (Pediatrics 2002;110:1304-6).

Adults with special health care needs deserve an adult-focused primary care physician, according to the statement.

Among the "first steps" for ensuring a successful transition, as outlined in the statement, are preparing and maintaining an up-to-date medical summary that is portable and accessible, and creating a written health care transition plan by age 14 along with the patient and patient's family. However, in addition to a lack of formal policies for transferring patients, the survey showed that a third of respondents had patients over age 22 years in their practice.

About half (47%) of these patients had special needs, and all of the patients over age 24 years had special needs, Dr. Burke of Brown University, Providence, R.I., reported.

Categories of transfer that emerged from the survey included "age out," "drop out," "forced out," "hang out," "move out," and "transfer out." (See box.)

About 19% of adolescents in the practices dropped out overall, but only 7% of those with special needs dropped out. Furthermore, only 7% of adolescent overall "hung out" after age 22 years, while 28% of those with special needs "hung out" after age 22 years," Dr. Burke noted.

The respondents completed a 13-item questionnaire about office policies, procedures, and processes for transferring adolescents with and without special health care needs.

Responses indicated that less than 3% of physicians believe transition should begin in early adolescence, 64% thought transition should begin 1 year before transfer, and 28% said transition should occur at the time of transfer.

About a third (30%) reported difficulty with transferring adolescents to adult care overall, and half had difficulty transferring those with special health care needs.

Also, only 31% provided written transfer summaries to accepting adult providers and only 18% had direct contact with those providers.

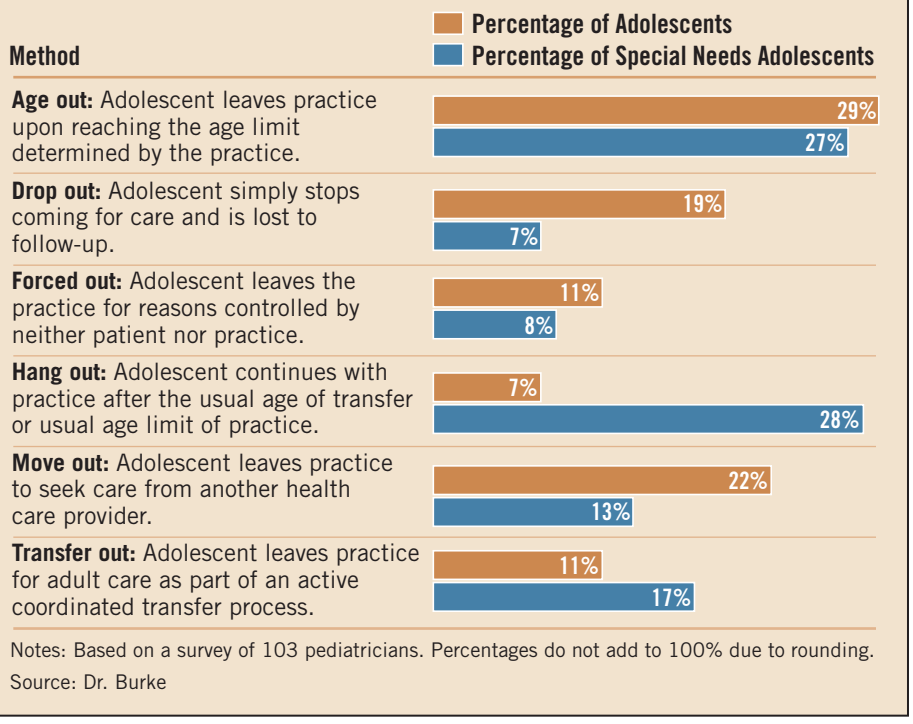
The findings suggest that additional efforts to educate physicians and promote the guidelines are needed.

"We are at the beginning of a process that will have challenges for both pediatric and adult care providers," Dr. Burke said in an interview, noting that a number of initiatives are underway to promote the use of the guidelines in Rhode Island.

A similar study of physicians who will be accepting adolescent patients (including internists and family physicians) is underway, and a guidebook on the subject of transfer of care for both pediatric and adult health care providers is in development, Dr. Burke said.

Models for transition and transfer to adult health care also are being developed in a collaborative effort that includes both pediatric and adult care providers, the Rhode Island Department of Health, and health care plans, he noted. ■

Methods of Transfer from Pediatric to Adult Care



Notes: Based on a survey of 103 pediatricians. Percentages do not add to 100% due to rounding.
Source: Dr. Burke

Value-Based Competition Seen as Health System's Future

BY NELLIE BRISTOL
Contributing Writer

WASHINGTON — Schemes measuring the quality of health care services against price will emerge in some local markets for several procedures in the next 2 years, Secretary of Health and Human Services Mike Leavitt said at a meeting on health information technology sponsored by eHealth Initiative and Bridges to Excellence.

Within 5 years, Mr. Leavitt said, the term "value" will become part of the health care lexicon. "Within 10 years, value-based competition will have truly emerged."

Working toward that goal are six pilot projects being conducted by the Ambulatory Care Quality Alliance (AQA), Mr. Leavitt said. Supported by the Centers for Medicare and Medicaid Services and the Agency for Health Care Research and Quality (AHRQ), the pilot projects are testing approaches to aggregating and reporting both public and private data on physician performance. According to AQA, the programs "will not only measure quality, but will identify those high quality providers who are able to deliver efficient care to patients, avoiding unnecessary complications and cost."

Dr. Carolyn Clancy, AHRQ director, expanded on the purpose of the projects. "These pilots will begin to pave the way for showing how we can use the same set of measures … to try to figure out how can we report publicly on performance and, at least as important although probably not as rapidly, how do we get that information back to providers so they can improve." She added that other sites would be added to the project shortly.

"We expect that when completed, the knowledge we develop through the AQA pilots will provide a comprehensive national framework for performance measurement and public reporting," she said.

Although measurement will be conducted locally, Dr. Clancy said, it will still be important to have one set of measures used nationally. "If we're competing on different types of measures, we're not going to make any progress," she said.

AQA is a national coalition of 125 physician, consumer, business, insurer, and government organizations that are working to develop strategies for measuring, reporting, and improving performance at the physician level. The group developed a "starter set" of 26 standard performance measures last year that AQA says is "now being incorporated in physician contracts and implemented around the country." Measurements for hospital care are being developed by the Hospital Quality Alliance.

Mr. Leavitt said that, in addition to those two national alliances, he knows of 29 community-based quality measurement efforts, driven not only by businesses but also by physicians.

"The force that I believe must drive quality will be those who provide it, and the force that I have seen learning to measure quality [is] the physicians," he said. "This cannot simply be the MBAs ganging up on the MDs. This has got to be a collaborative effort because in every case where quality has been measured by one side without the other, it's been ineffective and less efficient."

Measuring quality is a key component of the Bush administration's policy to increase transparency and value in health care purchasing and delivery. The policy requires federal health care purchasers, including Medicare, Medicaid, and the Department of Veterans Affairs, to encourage the use of health information technology, share information about procedure prices, develop quality of care measures, and develop and identify approaches that facilitate high quality and efficient care.

Part of the effort is to define "episodes of care" for frequent procedures that can be used as units by which to compare costs among providers.

"The important thing is that insurance companies and larger payers like the government are able to present their information in a form that the data can, in a privacy- protected way, be assembled into episodes of care for comparison," Mr. Leavitt said. "What is a hip replacement? What expense ought to be put into that bucket so we can compare one hospital or one physician to another?"

Mr. Leavitt and Dr. Clancy said the Bush administration's goal is to merge the insurance market power of the federal government with that of the private sector to move value-based competition along.

"During the next several months, we're going to see a tremendous push to combine the purchasing clout of the federal government with the health care buying power of the top 100 private employers in America—a public-private partnership on a scale we've never seen before to help health care consumers make more informed decisions about health care," Dr. Clancy said. ■