



Culture clash: Kids with chronic illness face tricky transition to adult care

By Denise Trunk

GAINESVILLE, Fla.—For young patients who grow to adulthood with a chronic illness, leaving behind the pediatrician who may have saved their lives can be a tough transition.

More than half a million children with special health-care needs will turn 18 this year, the first generation to reach adulthood since sweeping medical advances ensured an unprecedented number would survive congenital conditions that until recently would have killed them. The influx is straining an already burdened health-care system, and patients and their physicians are feeling the added stress, according to a study by researchers at the University of Florida's Institute for Child Health Policy appearing in the current issue of *Pediatrics*.

“We are looking at the very beginning of that wave, because this is the first generation to turn 18 since the technology and treatments have allowed them to survive to adulthood,” said lead researcher John Reiss, Ph.D., policy and program affairs chief at UF's Institute for Child Health Policy. “That number will grow, and this will put phenomenal pressure on adult medicine.”

Doctors liken it to a culture clash.

Young patients must say goodbye to the physicians they trust and who often took a team approach to their care, incorporating the opinions of many specialists to optimize a treatment plan for ailments such as cystic fibrosis. Many adult practitioners, meanwhile, tend to work more independently and are less familiar with how to manage these complex cases because they haven't routinely encountered them in standard practice. The issue can be costly, both physically and financially, said UF research associate Robert Gibson, Ph.D.

“It is like waking up in France one day,” Gibson said. “You don't speak French and you have no idea how to get around the city and you say, ‘Wait a second. How did I get here?’”

Pediatric hospital systems or practices generally use the ages of 18 or 21 as the cut-off for services, and about 600,000 patients with chronic illnesses are now reaching adulthood every year, Reiss said. Nearly 40 percent of the patients living with childhood-onset cystic fibrosis, for example, are 18 or older, according to the Cystic Fibrosis Foundation's National Patient Registry. As these patients age, their care can be complicated by reproductive issues and other ailments, such as diabetes or osteoporosis.

Past studies have shown the transition isn't easy even for the average healthy adult — often because of lack of insurance — and many drop out of the health-care system until they become sick. However, a smooth shift is vital for young adults with chronic illness, who cannot afford to experience a lapse in care, Reiss said. Yet these patients often

must switch doctors at a time when they, too, are least likely to be covered by health insurance, in part because of their higher rates of underemployment and unemployment.

Until recently, physicians may have handled one or two such individuals a year, and it was possible to work around the system, Reiss said.

“You didn’t need to think about a population-based approach to handling the problem. You could take an individual patient-based approach,” Reiss said.

To learn how patients make the leap into adult medical care, UF researchers interviewed 143 patients, families and health providers about their experiences with health-care transitions. Study participants were separated into 34 focus groups and answered questions about which factors made transitions successful or unsuccessful.

Researchers said many patients reported difficulty in receiving adequate pain relief after transitioning to an adult practice. Others were concerned about quality and comprehensiveness of care; some were the first patient their adult physician had ever seen with their particular disease.

Researchers also found that a mutual trust forms between pediatric patients, their families and their health-care providers. Saying goodbye to the doctor who has handled their care since they were diagnosed can be very difficult for patients, and that bond can present a barrier to effectively transitioning into adult-oriented medicine. Patients and families surveyed said they perceived pediatric staff to be more available for questions and emotional support.

Patients and families whose outlook focused on the future were more likely to experience a smooth transition, the study showed. Gibson, who conducted the study’s data analysis, said it was necessary for patients and their families to look at the change as part of the developmental process.

“The people that we talked to who were most successful understood transition from the moment the child received the diagnosis,” Gibson said. “Just like with a healthy child, you anticipate they are going to go to college or live independently in a community. There are things you do developmentally throughout their childhood to prepare them for that early on.”

UF researchers say the results suggest the medical community may need to create a more consumer-friendly medical system that would break down barriers to age-appropriate care, improve doctor-patient communication and incorporate a protocol for handling the transition. Internists and other adult practitioners, meanwhile, should talk to pediatricians about patients’ conditions and treatment strategies at the time they switch practices, Reiss said.

Elizabeth Tong, M.S., a clinical research nurse at the University of California, San Francisco’s division of pediatric cardiology and an associate clinical professor at UCSF’s School of Nursing, said the Reiss’s research spotlights the need for health professionals to tailor specific interventions to this population.

“Young adults with chronic health conditions is an emerging and growing group of patients, and health professionals as a group are still relatively inexperienced in understanding what are the medical, social and financial needs of young adults,” Tong said. “Qualitative analysis work by Dr. Reiss and others allows us to directly hear from patients what their needs are and how the current system is or is not meeting their needs. This input from patients provides the necessary groundwork for developing appropriate and meaningful interventions and care.”

Educating patients, their families and medical personnel is necessary to address the needs of this growing population of special needs patients, Reiss said.

“It may require the medical system to reorient itself toward the needs of patient, rather than the provider,” he said, “to the benefit of everyone.”