

Special Theme Issue: Care Transitions for Young Adults with Special Health Care Needs, Volume I

This month we bring to you a collection of articles about the difficult transition many young adults with special health care needs (YASHCN) face as they graduate from pediatrics to adult medicine. This transition has implications not only for medical care but also for complementary services related to education, job placement, and independent living. In Volume I, we present the rationale for providing an excellent medical transition. Volume II, in contrast, will focus on “resources” YASHCN and their families should know about regarding legal rights, insurance, reproductive health, and the needs of special populations—namely cancer survivors. Many thanks to Michael Landry, MD, and David DeLaet, MD, for organizing this important series.

—Priya Radhakrishnan, MD

EDITORIAL

“It Was Awful, Really Awful!”: Improving Transitions of Care

Michael Landry, MD, MSc

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In 1985, as a high school junior, I began my odyssey in working with children and young adults with special health care needs (YASHCN). That summer, I volunteered at Camp Pelican, an overnight weeklong residential camp for children with special pulmonary needs, including ventilator dependency, severe asthma, and cystic fibrosis (CF). As a 17-year-old counselor, I was not much older than my three campers (Charlie, Buddy, and Kevin, all age 15). At orientation, I learned that the life expectancy for my two campers with CF was 18 to 22 years. It amazed me how they wanted to “have a normal life” without all the interruptions that their chronic medical conditions seemed to impose on their teenage lives. We talked about their futures. They dreamed of finishing school, finding the perfect girlfriend, and one day having a family—all the things that “normal kids” their age mentioned when discussing their future. Although they talked about the probability of not living to see these dreams fully realized, their biggest fear was their transition from their pediatric providers to the unknown world of adult medicine. They had grown up in the medical arena and had seen more doctors than they cared to remember. But horror stories of other patients who had transitioned before them made this an anxiety-filled experience. They had grown up with their pediatric providers and felt safe with them. Who knew what the future would hold.

Entering medical school, I continued my work with Camp Pelican and saw the same issues repeatedly played out for these young adults transitioning to adult providers. Opportunities for improvement were everywhere. The end of medical school heralded my highly anticipated entrance into the internal medicine-pediatric residency program where I knew I would make a difference. Over my four years of training, I honed my skills and learned more about adolescent medicine, chronic diseases of childhood, and the inadequate transition that the health care system provided

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Lost in Transition: Young Adults with Special Health Care Needs

David E. DeLaet, MD, MPH

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Young adults with special health care needs (YASHCN) represent a growing population of patients that are currently or will soon be receiving care in adult-oriented health care systems. YASHCN include individuals with a wide range of chronic physical and mental health conditions as well as those with developmental and mental disabilities. As a group, they often face unique challenges in their transition to adulthood in both health care and non-health care domains. In this issue of *SGIM Forum*, articles will highlight many of these challenges and offer insight to addressing many of the obstacles to achieving effective, appropriate long-term care for these individuals.

Advances in medicine over the last several decades have resulted in a significant increase in the number of pediatric patients with chronic medical conditions who survive to adulthood. For example, whereas the median age of survival among individuals with sickle cell disease was estimated to be 14.3 years in 1973,¹ more recent data have demonstrated that 85% of such patients now survive to 18

years of age.² Today, a comparable proportion of patients born with cardiovascular anomalies are expected to reach adulthood.³ Likewise, the median predicted age of survival for patients with cystic fibrosis has risen from 25 in 1985 to 37.4 in 2007.⁴ Similar trends of improved survival have been seen for pediatric and adolescent patients diagnosed with malignancies and perinatally acquired HIV infection.^{5,6} Recent estimates suggest that the prevalence rate of mental disabilities in the non-institutionalized US population is about 7.8 people per thousand while the prevalence rate for developmental disabilities is about 11.3 people per thousand. That said, approximately 1 million individuals with mental challenges and developmental disabilities are likely to be transitioning to adult medicine over the next five years.⁷ Additionally, there are 2.4 million non-institutionalized adults age 18 to 26 with serious mental illness.⁸

Despite the large numbers of YASHCN needing to transition to adult medicine, data suggest that the organization of our current health care system and its adult-oriented medical centers are poorly prepared to meet this demand. A recent survey of 1,500 non-elderly adults with disabilities reported that one half had to postpone care or had difficulty in acquiring needed medications or medical equipment.⁹ It has also been shown that, among young adults with mental health conditions, inpatient admissions increase during the age of transition, perhaps suggesting limited access to ambulatory services.¹⁰ Additionally, observational studies have suggested worsening glycemic control in patients with type I diabetes

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Why Our Patients Deserve Our Time

Ann Nattinger, MD

But with the advent of newly designed health systems in the Affordable Care Act, I would argue we have to fight for a system of care that works for our patients. Not every patient needs more face time from their primary care team, but many do.



The men in my primary care practice are usually sicker than average patients. Like most women physicians, I attract a much higher percentage of women than men into my practice; many of these women are fairly healthy. In contrast, the men who come to see me are often referred because they haven't done well with someone else.

A particular male patient of mine stands out as having taught me a lot about caring for patients. Earlier in my career I would spend about three months yearly attending on inpatient ward services, and Tudy B. was a patient who I first met during an inpatient stint. He was an older patient of Italian heritage and frankly would not have chosen a woman as his primary care physician under normal circumstances. Although I like to think that I develop positive rapport with most of the patients I see, I was surprised when he asked if I would care for him upon hospital discharge.

I soon learned one reason that Tudy likely had not thrived with his previous physician. Tudy needed to develop trust by spending time talking with his physician, and this process fit poorly into the 15- to 20-minute appointment slots that most of us are allocated for primary care visits. This was particularly true for a man with Tudy's formidable problem list, particularly longstanding and poorly controlled hypertension, heart failure, and associated sequelae. In my attempt to meet Tudy's needs without crippling the rest of my schedule, I took to seeing him dur-

ing non-clinical time. This is the kind of thing that can decimate your academic time, but every once in a while you have to break your own rules.

I saw Tudy frequently, usually twice a month—partly to tinker with his diuretics and ACE inhibitors and partly to establish and maintain trust. Essentially, we developed a therapeutic relationship. Again, he surprised me—this time by how well he did. He stopped smoking, took his medications, and ate fewer salami sandwiches. His kidney function held its own for quite some time. In the course of these visits, I learned a lot about the history of Milwaukee and realized Tudy had many similarities to my own father. For example, both of them told me of the profound effects of seeing signs saying “NINA” in the storefronts when they were young men looking for jobs. In Tudy's world, “NINA” meant “No Italians Need Apply,” while in my father's neighborhood, it was “No Irish Need Apply.” Over time, I had gained Tudy's trust and understood his values fairly well.

From time to time, I meet with insurance company medical directors about the performance of our practices. In anticipation of one of these meetings, I was told that the insurer wished to discuss one of my faculty who was thought to be “churning” patients, which turned out to mean that he was seeing his patients with chronic illness more often than the norm. I braced myself to defend my faculty member, but

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the meeting went very well because in the interim the insurer had done more data analysis and learned that the outcomes of patients seen by this faculty member were substantially better than expected. It appeared that bringing certain patients in for more than the expected number of visits was somehow beneficial for glycol-Hb levels and blood pressure readings.

I cannot help but think that some of the better-than-anticipated outcomes for Tudy and for my faculty member who was initially thought to be “churning” had to do with building rapport—or connectedness—with patients. The relationship of frequency of visits (or visit time) and outcomes is fraught with selection bias and difficult to study. However, some data support a relationship between physician-patient connectedness and quality of primary care.¹

Undoubtedly, we are all aware that health care costs in the United States are higher than in other afflu-

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A Day in a Transition Practice

Peter Bulova, MD

Dr. Bulova is an assistant professor of medicine at the University of Pittsburgh Medical Center and is director of the University of Pittsburgh Adult Down Syndrome Center.

As an academic internist trying to find my niche, I began seeing adults with Down syndrome as they transitioned from pediatric services. I see patients age 16 to 65 and beyond. There is a new demand for internists caring for patients who have special needs and are living longer and healthier lives. Life expectancy for people with Down syndrome, for example, has increased from nine years in 1929 to almost 60 years today.¹ If the general population enjoyed the same increase, we might live to be 350.

When I began our transition clinic, I had limited experience with transitions or patients with special needs. I did, however, have enthusiasm, an outstanding mentor, and great support from colleagues and faculty. Our clinic began accepting patients once a month nine years ago, and today it operates one-half day per week. This article provides a view of the needs of this special population from the perspective of real patients.

Valerie

“Don’t shake her hand,” the caregiver reminded me the first few times I saw Valerie, a very pleasant woman who is in her 30s and has Down syndrome. To Valerie, the handshake signifies the end of the doctor’s appointment and prompts her to gather her things to leave, even if she just started the appointment. I instead begin our visits with a wave hello.

Theresa

During her first visit to our clinic, Theresa, a patient who is in her early 40s and has Down syndrome, eloquently described a problem with chronic diarrhea that had persisted for decades. Her condition created daily issues and fostered a fear of leaving the house and not being able to locate a bathroom. Despite an extensive workup for liver disease, no diagnosis had been found. She had been told, “That’s just a part of Down syndrome.” Of the few medical problems we find to be common in patients with Down syndrome, key among them is celiac sprue disease.² After treatment for this disease, Theresa’s diarrhea resolved completely, and she remains symptom-free.

Brenda and Terry

Because Down syndrome is known to be associated with Alzheimer’s disease, the caregivers and physicians of patients with Down syndrome often fear that any decline in the patient’s function might indicate the onset of dementia. Since Alzheimer’s disease is a diagnosis of exclusion, it should not be made without a thorough workup.

Brenda is a nonverbal woman I began seeing in her 50s, when she was referred for “new psychosis and onset of Alzheimer’s.” She had reportedly begun trying to remove her shirt in public—a new behavior for her. Discussion with her caregiver revealed that Brenda had recently ex-

perienced a 15-pound weight loss despite her recent dietary habit of drinking milkshakes and avoiding other foods. An x-ray revealed a hiatal hernia. It turns out that Brenda had been trying to loosen her collar to the point of ripping off her shirt due to reflux. Her new behaviors were reversed with ranitidine.

Terry was reported to have experienced memory loss and a significant decline in skills. During his first visit, he was nonverbal and asleep in his wheelchair. Testing showed an initial thyroid-stimulating hormone level of more than 250 uIU/mL. Treatment of severe hypothyroidism and sleep apnea dramatically improved his memory and function.

Many of our patients are referred to us by Kishore Vellody, MD, who runs the Down Syndrome Center at Children’s Hospital of Pittsburgh. In most cases, the major medical conditions associated with Down syndrome present early in life. While about 50% of our patients have a congenital heart defect,³ these defects have invariably been corrected before I see the patients as young adults. While leukemia is common, the majority of cases occur before age 20.⁴

I am always happy to see referrals from Dr. Vellody’s clinic for two specific reasons. First, I can see the patients in a routine visit. Transitions are remarkably harder in a time of crisis. It is difficult to deal with urgent issues, refer to multiple new subspecialists, and begin invasive diagnostic workups when meeting a patient for the first time. Pouring through hospital records and sorting out laboratory results while trying to build a relationship with someone in crisis is much more difficult. Second, all of Dr. Vellody’s patients come with a comprehensive progress report that summarizes past problems

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“Finding day programs or job programs is vital to the quality of life of our patients. Services to help maintain existing opportunities and introduce new ones are just as crucial.

A Case of a Young Adult with Myelomeningocele: A Transition to Adult Health Care

Laura Dingfield, MD (presenter), and Allen Friedland, MD, FACP, FAAP (discussant, in italic)

Dr. Dingfield is a PGY-4 in the combined Internal Medicine and Pediatrics Residency Program at the University of Pennsylvania/Children's Hospital of Philadelphia, and Dr. Friedland is an associate professor of internal medicine and pediatrics at Jefferson Medical College and program director of the Internal Medicine-Pediatrics Program at Christiana Care Health System.

A 21-year-old woman presents to an internist to establish care. Her past medical history is significant for myelomeningocele (spina bifida), T-10 paraplegia, neurogenic bladder status-post many surgical bladder revisions and Mitrofanoff, ventriculoperitoneal shunt for hydrocephalus, seizure disorder, migraine headaches, recurrent urinary tract infections, cecostomy for chronic constipation, and depression. A condensed summary of her medical and surgical history was prepared by her pediatric team.

Spina bifida is a congenital chronic condition that has effects on multiple systems (e.g. neurologic, orthopedic, urologic, psychologic, social, growth, genital, gastrointestinal, respiratory, and oro-motor), the family, and the health system. The defects arise by the end of the fourth week after conception and result from failed closure of the neural tube, with improper formation of the spinal cord, dorsal vertebral bodies, and overlying tissues. The long-term prognosis is based on several factors, including the location of the spinal lesion, urologic abnormalities and renal disease, and the presence or absence of hydrocephalus. As is the case with many congenital or childhood-acquired conditions, interaction between the patient and the family—and successful transition to the adult health care system—are critical to long-term prognosis.

The patient was previously cared for by a hospital-based pediatrician and pediatric specialists. Previous attempts to transition her to an adult primary care physician and urologist closer to her home had recently failed, as the physicians refused to care for her because she was “complicated” and suggested the family

move to another location in order to receive specialized care.

More than a half million children with special health care needs become adults each year, and more than 90% of these individuals survive past age 30, including those with spina bifida. It is critical for providers caring for adults to have a better working knowledge of how to address the medical and psychosocial needs of these patients.

Transition of patients into the adult health care system is a challenge to patients, families, pediatricians, and providers of adult care. It is now recommended that between ages 12 and 14 certain skills be taught and reinforced with the expectation that the transition to adult care will begin between ages 18 and 21. Transition is a high-risk endeavor for many individuals with childhood acquired conditions, as it has been shown that outcomes are worse and mortality is higher in many conditions during this time period. To help facilitate safe transition of patients with complex childhood-acquired conditions, it is recommended that detailed health summaries be prepared for adult providers and that verbal signout be performed, if deemed necessary.

The patient was recently hospitalized in a children's hospital for a urinary tract infection the week before her 21st birthday, when she was expected to transition to adult care. She was treated with intravenous antibiotics in the hospital and discharged on an oral regimen. On review of her records, she has spent 216 days of the previous two years in the hospital secondary to upper urinary tract infections. She is supposed to self-catheterize her Mitrofanoff at least every four hours

while awake and irrigate her bladder with acetic acid three times per day. However, she reports that this regimen has been difficult to follow.

Individuals with congenital or childhood-acquired conditions may have comorbidities or prior treatments/procedures that are unfamiliar to providers of adult care. Knowledge of these comorbidities and standard treatments is essential. For example, neurogenic bladder with physiologic and/or anatomic abnormalities of the urinary tract is a hallmark of patients with spina bifida and is the leading cause of mortality in this population. Prevention of urinary tract infections and elevated urinary tract pressures is needed to prevent or reduce renal injury. Improvements in surgeries, clean intermittent catheterization (CIC), and medications to lower bladder pressures, minimize urinary reflux, and prevent urinary tract infections have led to increased survival. Bladder management is required by the majority of adult patients. Most adult patients use CIC via the urethra or an abdominal stoma that enters the top of the bladder more commonly than indwelling urinary catheters. In our patient who is wheelchair bound, her abdominal stoma (Mitrofanoff or appendicovesicostomy) is the conduit from her abdominal wall to upper bladder. This allows for more privacy, easier access, and less parental dependence to comply with CIC.

The patient admits that a bout of depression preceded her most recent urinary tract infection. During that period, she forgot to self-catheterize regularly. She reports feeling “down” about her immobility and chronic medical conditions and

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Transitioning from Pediatric to Internist Physician for Adults

Deborah and Joseph Switalski

Mr. and Mrs. Switalski have two children with special health care needs and currently live in Phoenix, AZ.

As our children grow, we as parents must also grow with them and help them transition to the next level. The transitioning starts in school and begins the series of steps our children need to take toward independence. The biggest transition of all is the transition from high school to post-high school and then more dramatically from pediatrician to internist. In some ways, the transition from the pediatrician can be one of the hardest because it involves the person who has consistently watched over our children for the longest time. If your family has a child with special needs, this transition can be even more unnerving, as it can mean moving from a secure and safe relationship to an unknown source and level of care. In our case, we have two sons born with cerebral palsy, which we later learned was a result of a fairly rare condition known as Pelizaeus-Merzbacher disease that prevents the myelin sheath from fully forming and covering the nerve tissue. Both sons are alert, social, and small in stature, with significant hypotonic and spastic muscles. Our older son has asthma, allergies, and a generally compromised respiratory system that leaves him vulnerable to frequent infections and periodic episodes of pneumonia. Our younger son has had four different intra-theatal pumps installed over a 17-year period in order to deliver baclofen to his lower extremities to prevent constant spasms, clonus, and pressure from his knees pressing together. Through all of the hospitalizations our sons have endured, we could count on the children's hospitals in Detroit, Kansas City, and Phoenix to provide not only great and responsive medical care but also the extra measure of compassion that comes from every aide, nurse, medical student, intern, resident, attending, hospitalist, and physician specialist that cared for them. This extra level of

care and love appears to be a hallmark of the children's hospitals we have encountered regardless of physical location.

As we look to make this transition, we need to understand the differences between staying with a family medicine doctor or moving to an internist or a specialist that our child will need. Choosing a primary care physician can be an overwhelming quest, as it requires understanding the differences between them and then deciding which one will offer the best support system of care. For some, the choices are decided for them by their work or further schooling—for others, by state support.

Many pediatric offices offer a multidisciplinary team (MDT) to provide the care for children with special needs. The benefits of an MDT are tremendous. In an MDT, one person becomes the main coordinator of care based on needed medicine and therapies as well as the child's medical status. Regular meetings ensure key issues are brought up and discussed to develop *coordinated*—not needlessly repetitive—care. If the team holds clinics, specialists that families don't always encounter, like nutritionists, social workers, and occupational therapists, are available to stop in and let families know about available resources. In addition, we have found that all providers are notified when our child requires hospitalization. As a parent, it was reassuring to have the physicians and specialists stop by our child's room to see him even when admitted for a procedure not in their area of expertise. This personal touch was somehow prevalent in the pediatric arena regardless of episode. With all subsequent specialist appointments, information flow was coordinated, allowing everyone to understand the details of the hospitalization. The fact that the system supports and

encourages physicians to get to know our children holistically and personally seems to be a hallmark of a children's hospital. This support system is very comforting, but it creates anxiety when similar support systems are not available in the adult setting where several doctors work as a team to provide care. The idea of screening new doctors in separate offices—knowing that we are responsible for obtaining all necessary information—is an overwhelming burden. Without the electronic health record (EHR) in place, obtaining, transferring, or ferrying our children's appropriate health records to separate offices becomes a full-time job. I don't have to mention how frustrating it is to have to complete the same sometimes-lengthy medical forms for each new facility or physician visited.

The community health support system options are simpler during the pediatric ages and are based mostly on services connected to the hospital. Once special needs children reach an adult age, their options regarding social agencies, insurance plans, and hospitals are huge and varied and so overwhelming that one doesn't even know where to begin to ask questions. The insurance plan becomes the main guide—not the services provided by the hospital. For us, simple things like finding an urgent care clinic, eye doctor, dentist, or a lab filled us with uncertainty. We now know we need to do a lot of calling around first to see where our sons can be seen. For example, while we were in the transition process, our older son had an ear infection on a weekend. Not knowing yet where to go, I took him to his usual weekend urgent care clinic. We had been warned our sons might be turned away for care there after a certain age. That is exactly what happened.

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Moving Neighborhoods: Subspecialty Care and the Transition to the Adult-oriented Patient-centered Medical Home

Joseph Truglio, MD, and David E. DeLaet, MD, MPH

Drs. Truglio and DeLaet are assistant professors of medicine and pediatrics at the Mount Sinai School of Medicine.

The transition from pediatric to adult subspecialists is a significant challenge for adolescents and young adults with special health care needs (YASHCN). More and more children are surviving to adulthood with increasingly complex conditions and are followed by numerous subspecialists. Given this changing dynamic, the transition to an adult-oriented patient-centered medical home (PCMH) becomes less like moving homes and more like moving neighborhoods. General internists who care for these patients need tools to help them facilitate a smooth transition of subspecialty care and to co-manage their patients with multiple subspecialty teams.

With the current system, numerous studies demonstrate increased morbidity during the transition of subspecialty care. Type 1 diabetics experience worsened glycemic control.¹ There is an increased incidence of graft failure in transplant recipients.² Patients with congenital heart disease have increased morbidities and need for intervention—particularly when there is a lapse of subspecialty care during the transition process.³ The transition of subspecialty care is also a source of anxiety for pediatric providers, patients, and families in part due to the long-standing relationships with these subspecialists.⁴

Every year, a growing number of children with special health care needs enters into this potentially hazardous transition process. Roughly half of all patients living with cystic fibrosis are adults,⁴ and there are more adults currently living with congenital heart disease than children with these conditions.⁵ Similar epidemiologic shifts are seen in patients with sickle cell disease,⁶ pediatric transplant recipients, and survivors of pediatric malignancies.

General internists and family physicians now provide care for the vast majority of these patients. Of the nearly 1 million adults with congenital heart disease in the United States, for example, less than 100,000 attend specialized adult congenital heart disease centers.⁵ Providing this care is extremely complex and time consuming. The average adult primary care physician in the United States shares patients with numerous adult specialists and subspecialists as well as visiting nurses, physical and occupational therapists, and mental health professionals. The prospect of adding pediatricians and pediatric subspecialists to this list is daunting. Further, many adult providers may not feel as though they have adequate time, reimbursement, or training to coordinate the transition process or to provide ongoing care to adults with special health care needs.⁷ This is compounded by a perceived lack of adult subspecialists capable of treating adults with childhood conditions. There is an increasing need for strategies to improve outcomes during the transition process and to optimize co-management between the PCMH and its neighbors—the subspecialists.

Understanding the overall transition process will assist the general internist in facilitating the transition of subspecialty care. Transition planning should begin at age 12, with patient- and family-oriented discussions at each medical home encounter.⁸ Beginning by the age 14, a written transition plan should be developed. This portable medical summary should be reviewed and updated through and beyond age 18. For children with special health care needs, the management of their chronic conditions should be included in this plan. Particular attention should be paid to disease-specific information, self-care competencies, and the plan

for transitioning subspecialty care. Generic and disease-specific portable medical summaries are available online.⁹ The actual transition of care typically takes place between ages 18 and 21. Ideally, this should occur when the patient's condition is relatively stable. Subspecialty teams should be involved in the process from start to finish and should identify adult subspecialty providers on the receiving end of the transition.

Once the transition occurs from the pediatric to the adult-oriented medical home, the general internist will co-manage the patient initially with the pediatric and adult specialists. In 2010, the Council of Subspecialty Societies of the American College of Physicians published a position paper titled “The Patient-centered Medical Home Neighbor: The Interface of the Patient-centered Medical Home with Specialty/Subspecialty Practices.”¹⁰ This position paper outlines four forms of interaction between the PCMH and their neighbors (PCMH-N): pre-consultation communication, formal consultation, co-management, and transfer of the patient to the specialty/subspecialty PCMH for comprehensive management. The paper does not specifically address the complex transition process involving PCMH and one or more PCMH-N for YASHCN. However, the general concepts of co-management are useful in guiding the adult-oriented PCMH provider in managing YASHCN alongside their subspecialty providers.

The ACP suggests three forms of co-management between the PCMH and the PCMH-N. In a “shared management for the disease” model, the subspecialist provides advice but does not actively manage any aspect of the patient's care. In a “principal care for the disease” model, both

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these young adults with highly complex care needs. As I thought back to my own transition experience, I realized that my personal journey from pediatric care to my internist was not much different. There did not seem to be any structure to the process, any handoff of information, or any communication about my future arrival. The burden fell on me to relate my medical history and current issues. As a healthy young adult, this suboptimal transition probably did not impact my health or well-being. As many young adults, I dropped out of the health care system, only resurfacing for an occasional visit to the PCP or the emergency room for periodic care. But the realization arose that many YASHCN might need more help bridging from pediatric to adult care and that if this transition were not handled well it might even cost them their lives.

As a junior faculty member, I started a transition clinic and slowly tried to change the world. I began to realize that transition of care was interpreted differently in the world of medicine depending on the audience. To the med-peds audience, transition of care most often focused on care transitions from pediatric to adult providers while the audience of internists and geriatricians considered care transitions to be the movement of the adult patient into different health care settings (e.g. inpatient, outpatient, nursing home). I found myself using clarifying terms like “*vertical transition of care*” (pediatric patients transitioning to adult medicine) and “*horizontal transition of care*” (adults transitioning across health care settings). I began my task of changing the transition world by forming the SGIM Transition of Care Interest Group with a focus on the vertical transition of care. Most of those in attendance in the early years were med-peds practitioners or internists who thought we were talking about horizontal transitions of care. We realized then that our task was daunting to bring this expanding patient population to light in the world of internal medicine.

In 2003-2004, I undertook a qualitative study to look at the attitudes and beliefs of sickle cell patients regarding their transitions. A quote by one of the patients, “It was awful, really awful!”, summed up the views on the transition process of our participants. The eventual publication of this paper was derailed by Hurricane Katrina and the subsequent scattering of my transition patients across the Southeast. However, eight themes emerged from the analysis of the data:

1. Patients’ experiences with their transitions of care were generally negative.
2. Some patients reported that they were transferred to adult health care providers without their knowledge.
3. Patients perceived that their pediatric providers spent more time with them, communicated better, and had better attitudes compared to adult providers.
4. Nursing and staff interaction was as critical as physician interaction in patients’ perceptions of treatment.
5. Family support and self-care were integral components of patients’ overall care.
6. Patients reported significant lack of control over their care while hospitalized but did exert more control outside of the hospital.
7. Patients desired more professional support, communication, encouragement, and education.
8. All patients believed there was a need for a structured transition program.

A few representative quotes highlight the opportunity to improve this process:

There is a big difference transitioning from your pediatrician to your adult doctor because when you are a kid, the doctors are more patient with you and treat you very nicely. As an adult, you get treated very badly.

There is a need for a transition program because it is totally different when you become an adult. It is a big adjustment.

Yes, there is a need for a program because kids are being catered to. Someone is always there for them. Patients need to start experiencing early what they will be in store for later because it is totally different. You’re lucky now if someone comes in and talks to you at all.

So, you may ask, why are we writing about this in the *SGIM Forum*? YASHCN are a population that is increasing at a greater rate than other populations, and the associated health care costs are significant. Berry et al. recently published a retrospective cohort analysis from 28 children’s hospitals with 1.5 million unique patients.¹ Their study reveals that children with a significant chronic condition affecting two or more body systems accounted for 19% of patients, 27% of hospital discharges, 49% of hospital days, and 53% of hospital charges (\$9.2 billion) in 2009 alone. In addition, this group had a 33% cumulative increase in size between 2004 and 2009. They conclude that “children’s hospitals must ensure that their inpatient care systems and payment structures are equipped to meet the protean needs of this important population of children.” In this issue of *Forum*, DeLaet highlights the increased life expectancy of these patients and the subsequent increased volume of patients. These patients will continue to migrate through the health care system and transition to adult care. This volume of patients exceeds the capacity of med-peds-trained practitioners who might feel more comfortable caring for this population. But, I argue, taking care of complex patients is what we, as internists, do best. An octogenarian with multiple systemic problems with a need for specialized services is not fundamentally different from a YASHCN.

How can we provide individualized care to YASHCN? Internal medicine
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PRESIDENT'S COLUMN

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ent countries. But we may not all be aware of the extent to which health status and outcomes are worse in the United States than in other similar countries. Among 17 wealthy developed nations, the United States has the highest prevalence of obesity and diabetes and the second highest death rate from ischemic heart disease.² Life expectancy at age 50 is also lower relative to the 16 other developed countries. It might be argued that these facts reflect barriers to care for the under- and uninsured. However, the US health disadvantage is not limited to those of low socioeconomic status. It is found even among those who have health insurance, a college education, and higher incomes.

Some of the US health disadvantage may be due to societal policies, such as those related to firearms or to the way the layout of many of our suburban cities facilitates driving rather than walking. But one does not have to practice primary care

very long to realize that the status quo with regard to expected length and frequency of visits is frustrating to both patients and providers. Studies of US patients vs. patients in other countries show that US patients are more likely to report episodes of low-quality, poorly coordinated care and miscommunication with their clinicians.² These are indictments of our "system" of primary care, and these apply to everyone—including those with access to services.

To me, these findings lead to a conclusion that many of our patients (especially those with chronic illness) need more of our time. Some tell me that I am naïve. We have a huge problem with the cost of medical care in this country, and the idea that primary care physicians should see fewer patients (i.e. be "less productive") will gain support from few. But with the advent of newly designed health systems in the Affordable Care Act, I would argue we have to

fight for a system of care that works for our patients. Not every patient needs more face time from their primary care team, but many do. Of course, others may benefit from e-mails in the place of office visits. Somehow in the past, we let others set our expectations for how to structure primary care practice. We need to take this opportunity to advocate for a system that we can believe in.

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and outlines ongoing issues that I may need to address. This is invaluable for making successful transitions and avoiding gaps in care.

Some of the challenges of the transition include the loss of access to services that are easily obtained for patients under age 21. The structure of school is invaluable for our patients, and there are not always resources available to provide daily routine once they have graduated from the school system. Finding day programs or job programs is vital to the quality of life of our patients. Services to help maintain existing opportunities and introduce new ones are just as crucial.

Manny

Manny is a 26-year-old patient who has made a smooth transition to our clinic. As I do with all of my patients, I make sure that I address Manny first before I begin talking

with family members who may have joined him for the office visit. I also make sure not to assume that I am more of an expert than the caregivers, whose coping strategies I gladly pass on to others.

Manny's body mass index is 24, and he takes great pride in his healthy appearance. I was happy to learn that he has a personal trainer who works with him twice a week. In fact, I talk about Manny frequently with other patients, many of whom have been told that being overweight is expected of individuals with Down syndrome. Hearing Manny's story inspires other patients to exercise.

David

David lives in a group home. One day, he became so agitated that he was admitted to our local psychiatric hospital. I never determined the cause of his acute agitation myself,

but I learned from a caregiver that someone had come to vacuum David's room, had encountered several piles of David's belongings on the floor, and had moved these belongings to David's bed not knowing that David had organized his belongings in a special way. The loss of organizational structure was debilitating to David.

I am always comforted to know that I do not need to be the one to diagnose every problem or solve every challenge that arises. Using the resources available—caregivers, family members, and trusted specialists—I never feel alone in caring for my patients. For example, while I might suggest that a person has sleep apnea, I appreciate the patience of our pulmonologists who work to find a creative diagnostic and treatment plan. Finding a plan is not always straightforward.

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MORNING REPORT

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wishes that she could lead a “normal life.” She graduated from high school but had to drop out of college one year ago due to recurrent illness and recently had to leave a part-time job because she was unable to physically perform the work. She would also like to live independently but is not sure that she can accomplish this. She is dependent on her working mother to help provide much of her care.

Though many adults with conditions like spina bifida have normal or near-normal intelligence, many struggle with psychological comorbidities that can profoundly impact their health and overall functional status. Depression, anxiety, attention issues, learning disabilities (especially non-verbal), memory problems, and abnormal executive functioning are particularly common among those with spina bifida. Quality of life is also impacted by the family’s beliefs in the patient’s capabilities, which may underestimate potential.

Resources available to patients with chronic disabilities like spina bifida vary across states. However, in many areas transportation assistance, educational accommodations, and housing resources are available. In addition, as a result of the Workforce Investment Act of 1998, states are required to provide vocational rehabilitation services to qualifying individuals. Neuropsychological testing may be useful to help identify which services may be available or appropriate for individual patients.

The patient agrees to referral for neuropsychological testing in order to assess whether she qualifies for state-run job training services, as well as referral to physical and occupational therapy to assist with physical independence and mobility. She agrees to a two-month follow-up visit.

In addition to age-appropriate preventive care and surveillance, individuals with childhood-onset conditions may require additional testing or screening. Patients with spina bifida require the adult provider to consider these issues:

- **Bone Health:** *Osteoporosis is prevalent in patients with spina bifida due to immobility. Adolescents and young adults with spina bifida may have more fractures than older adults and may present with redness and/or swelling without pain. Bone density screening is recommended, but consensus on timing of screening is lacking.*
 - **Cardiology:** *The prevalence of metabolic syndrome in individuals with spina bifida is at least 30%. These patients are at increased risk of diabetes and cardiac disease.*
 - **Functional Status:** *Up to 50% of ambulatory patients with spina bifida become non-ambulatory in adulthood due to altered biomechanics. Worsening kyphoscoliosis and pulmonary reserve occur as obesity and inactivity increase. Efforts should be made to encourage mobility through exercise programs.*
 - **GI:** *Many suffer from neurogenic bowel and must cope with fecal incontinence, constipation, or both. Regular attention should be paid to a patient’s bowel regimen in order to ensure a predictable and regular stooling pattern.*
 - **Nephrology/Urology:** *Yearly renal ultrasounds, urodynamics, laboratories, and blood pressure are recommended because a change in function may indicate a worsening neurological or urologic issue. Those patients with bladder augmentation may be at increased risk of bladder cancer in the future, but the current recommendation is against routine screening with cystoscopy and cytology for asymptomatic individuals.*
 - **Neurology:** *Though most VP shunt malfunctions occur in the first three decades of life, malfunctions in adults may present with slow changes in cognition and chronic headache. New ataxia, upper extremity pain, weakness, and nerve palsies may suggest symptomatic Chiari malformation, syringomyelia, or tethered cord. Gait, orthopedic, and bowel or bladder changes may also indicate symptomatic tethering of the cord (even if this was repaired in the past).*
 - **Ophthalmology:** *Many visual disturbances including strabismus, esotropia, exotropia, and orthotopia can occur in this population. Annual ophthalmologic examination should be considered.*
 - **Reproductive Health:** *Sexual education and counseling on reproductive health should be performed during the young adult years. Males with spina bifida may have impaired sexual function depending on the level of their lesion, and those with lesions above T10 are at increased risk of azoospermia. In terms of reproductive counseling, both men and women with spina bifida are at increased risk of having a child with spina bifida. Patients must be on much higher doses of folic acid to reduce this risk.*
 - **Skin:** *Pressure ulcers in areas with altered sensation in the lower extremities and sacral area are common. It is important to examine wheelchair-bound patients outside of the wheelchair in order to visualize the skin well.*
- Since transitioning to adult care, the patient has made significant strides over the past three years. In addition to her medical issues, care has focused on providing psychosocial support and addressing the patient’s issues of social isolation, low self-esteem, and depression. She now travels (two hours each way) by para-transit to her appointments, has held several jobs, speaks about the importance of successful transition to adult care for children with special health care needs, and has not been hospitalized in more than 16 months.

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Take Home Points

1. There is a large population of individuals with congenital and child-onset conditions that are living well into adulthood and need to transition successfully to the adult health care system.
2. Patients with spina bifida and other chronic diseases of childhood frequently have comorbid anxiety, depression, and impaired executive functioning, which negatively impacts physical health.
3. In addition to age-appropriate screening and health maintenance, patients with chronic childhood-onset conditions often require additional disease-specific considerations.

Suggested Readings and Resources

American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics* 2011; 128(1):182-200.

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mellitus,¹¹ increased incidence of graft failure in solid organ transplant recipients,¹² and increased rates of hospitalization among cystic fibrosis patients during the transition period.¹³ There are several factors that likely contribute to these adverse health outcomes. Surveys of both pediatric and adult providers cite poor communication as a significant barrier to the transition process.^{14,15} Internists also express concern about having insufficient training and inadequate support to appropriately care for YASHCN.¹⁵ Further, lapses in health insurance coverage often limit a successful transition, with many YASHCN becoming uninsured at age 19 because they have aged out of their parents' insurance plan or because they no longer qualify for public insurance coverage.

In addition to challenges in health care transitions, the needs of YASHCN in non-health care do-
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mains are also not being adequately addressed. Data suggest that approximately 20% of individuals with disabilities and more than one third of non-institutionalized adolescents with mental illness do not complete high school—more than twice the rate of their peers.^{8,16} Similarly, it is estimated that 35% of people with disabilities are employed compared to 78% of those without disabilities.¹⁶ Consistent with these findings, individuals with disabilities are much more likely than their peers to worry about not being able to live independently or being a burden to their families.¹⁶ YASHCN have also reported that they feel as if they are perceived as being asexual and often suffer a negative body image and low self-esteem.¹⁷ Perhaps not surprisingly, individuals with disabilities report much lower rates of life satisfaction.¹⁶

In light of the many difficulties faced by YASHCN as they transition to adulthood, it is imperative that adult-oriented health care systems institute strategies to better support this process. Enhancing collaboration between transferring pediatric providers and receiving adult providers would be a key initial step. By improving bi-directional communication over the course of the transition process, providers might better assure that the goals of the YASHCN are met in all domains of their lives. Further, providing adult providers with a heightened understanding of available resources to support YASHCN, including educational, vocational, and independent living opportunities, will likely lead to better health outcomes and patient satisfaction while simultaneously alleviating provider anxiety. A greater emphasis on the transition process and the long-term care of YASHCN in medical school and resident training curricula should be considered an important part of the education of future adult providers. Lastly, interventions that help to eliminate gaps in health insurance coverage as

YASHCN transfer to adult-oriented care centers would certainly have a positive impact.

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teams actively manage the patient with clear and discrete responsibilities. The PCMH remains the primary point of contact. Finally, in a “principal care of the patient for a consuming illness for a limited period” model, the PCMH-N temporarily assumes primary responsibility of care and is the first contact for the patient. The PCMH is kept up to speed and at times has primary responsibility of defined areas of care. The ideal model of care varies from patient to patient and may change as the patient transitions from a pediatric to an adult-oriented medical home. For example, a child with insulin-dependent diabetes may have his diabetes managed entirely by a pediatric endocrinologist, with his other health care needs managed by his pediatrician—a “principal care for the disease” model. After transitioning to an adult-oriented medical home, the internist may take primary responsibility for the patient’s diabetes management, referring to an adult endocrinologist for specific questions and advice—a “shared management of the disease” model. The critical element is that the PCMH and the PCMH-Ns all understand the co-management model and that the patient is in agreement and understands who his/her point of contact is.

Data-driven guidelines, educational support, and financial incentives are needed to improve outcomes as adolescents and YASHCN transition to the adult-oriented medical home. However, an understanding of the overall transition process and the use of concrete co-management models may serve as a framework for the general internist caring for these patients.

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When I asked where we should go, some local urgent care clinics were recommended, but no one was sure they were appropriate for our son or would take our insurance plan. Not knowing where to turn, I headed out the door to go home and start calling. Later, I was called back in, and the clinic provider examined my son’s ears, wrote a prescription, and then mentioned some possible places to go for special care. I knew at that point that I had to be better prepared in the future. Calls are now made ahead of time to a physician or agency based on personal contacts or other family recommendations. The question of insurance often comes up in deciding where to go next. Will the medical center or physicians group honor the same insurance plan as the pediatric facility? If not, what are the options? Do they see adults only or all ages? These seem like such small things, but to sit in a waiting room and be told that the clinic does not have equipment small enough to examine your son or that the group is not contracted with your current insurer can be scary and overwhelming. This scenario often occurs at referred adult facilities, and the parent is then charged with the task of pre-contacting the facility to make certain it can accommodate the special need or smaller body size.

We have been fortunate that we have found our way through all of this uncertainty and received a lot of positive support from our new physicians. The many tears shed and frustrations experienced in the search are now forgotten. I can’t help but wonder if some of it would have been less stressful if we had been better prepared by the pediatric facility and armed with a checklist of issues to consider before beginning the transition process and facing all of the new decisions that had to be made. A checklist might contain items such as:

- Recommendations for new internists familiar with pediatric care in systems that have the

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People come to our clinic for the first time with great trepidation. Those with special needs often are highly resistant to change, and the transition visit represents a large change. Many patients have had difficult experiences with new doctors and have a great fear of the unknown. Many are leaving the comfort of long-term pediatric care in addition to embarking on the changes of adulthood. After new patient visits, I often hear patients and their caregivers describe an enormous feeling of relief and gratitude.

While I feel a great sense of obligation in helping a population in need of good care, I also feel a great sense of reward in offering care, acting as a liaison with other medical providers, and becoming a stakeholder in the team of caregiver support that each patient develops.

Though the patients who use our clinic may seem specialized, they demand only the same level of diligence, attendance to best practices, strong communication channels, and empathy that other patients demand and receive.

My work in the Down Syndrome Center has garnered a great benefit: More than any other aspect of my job, this work has allowed me to develop closer relationships with patients and their caregivers and to learn more from them. For example, I know now that when a caregiver suggests that I not shake a patient's hand, there is a good reason.

Editor's Note: Pseudonyms are used for all patients described in this article.

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cine must continue to recognize the disparities in health care delivery for specific populations. Patient-centered medical homes (PCMH) have gained traction within the internal medicine arena as we attempt to deliver quality medical care for an aging population with increasingly complex medical needs. Let us not forget that PCMHs originated in the 1950s as a means for pediatricians and specialists to collaborate on delivering complex care to children with special health care needs. What better way to begin to craft structured transitions of care for YASHCN than to start coordination with pediatric teams that have been historically equipped to deliver this care?

Advocacy must continue to drive policies and legislation that enrich the lives and assist the caregivers of YASHCN. The Patient Protection and Affordable Care Act (PPACA) takes a step in this direction but fails to identify these YASHCN as a significant driver of health care utilization and expenditures. This will only continue to increase over time as more transition patients move into adulthood. Coverage of specialized services to allow patient independence as well as durable medical equipment and other specialized care needs are critical for success in their care.

Education reform must start for

students, residents, and fellows in providing primary and specialty care for this unique population. In her upcoming article (scheduled for publication in volume 2 of the special transition of care edition of *SGIM Forum*), Waite reports several studies that highlight the discomfort and lack of preparedness that new medical professionals feel in providing care to these patients. New trainees will participate in the care of YASHCN when the medical needs are more clearly understood and defined.

Finally, payment reform must change. Caring for a YASHCN can be extremely rewarding to medical professionals, but the financial reimbursement for the care of these patients is lacking. Medicare has adopted the annual Medicare wellness exam upon enrollment.

YASHCN are not offered a similar option upon transferring their complex chronic care from pediatric to adult health care providers. Initial visits with YASHCN require time to establish trust, build a team of specialists, and identify community services designed to best achieve the best outcomes for these patients.

Samuel Coleridge wrote in *The Rime of the Ancient Mariner*, "Water, water everywhere nor any a drop to drink."² Today, YASHCN often feel that there is "Health care, health care everywhere, but none of it seems

right for me." Recognition is the first step in correcting the problem. In this two-volume *Forum* edition, we have identified the issues facing YASHCN and their transition to internal medicine, including the scope of the problem and the issues faced by physicians, patients, and parents. We have also identified the need for revision of graduate medical education in this topic area and the need to revisit PCMH and PCMH-N structures.

In the next issue of *Forum*, tools and resources for YASHCN will be discussed in articles focusing on medical education curriculum reform, transitioning in non-healthcare domains, reproductive education and issues in YASHCN, tackling legal challenges, care of childhood cancer survivors, and dealing with insurance issues.

Our challenge to general internal medicine is to improve health care transitions for YASHCN so future YASHCN will say: "It was awesome, really awesome."

References

1. Berry JG, et al. Inpatient growth and resource use in 28 children's hospitals—a longitudinal, multi-institutional study. *Arch Pediatrics Adolescent Med* (published online December 24, 2012).
2. Coleridge S. *The Rime of the Ancient Mariner*, 1797. *SGIM*

COMMENTARY: PART II

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- specialists needed for the child's diagnoses;
- Recommendations for hospitals, physician groups, and clinic systems that are contracted with the child's existing insurance provider;
- A complete medical record assembled for parents so that they can present a complete patient picture of the special needs child to the receiving PCP, hospital, and physician group;
- A face-to-face meeting or phone conference between the child's

PCP in the children's hospital system and the receiving PCP to review the medical history and treatment plan; and

- A thorough review of records by the receiving physician to facilitate referrals to in-network specialists and urgent care facilities that are equipped to handle the needs of the patient.

The bottom line is that parents with special needs children know that such transitions are difficult and that they must assume the role

of advocate. However, it is much easier to approach that task with a partner. Someone from either the sending system (i.e. children's hospital) or the chosen receiving system should take a personal interest in making certain the child is cared for properly in the transition. This is best accomplished when all of the critical issues are addressed in a checklist and an open dialogue occurs with the parents as the checklist tasks are addressed and completed.

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