

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

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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 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 in-

terpreted 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:

continued on page 2

## EDITORIAL

continued from page 1

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.<sup>1</sup> 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 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 inde-

continued on page 3

pendence 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 well-

ness 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.”<sup>2</sup> 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*