Much has been written about the process of transitioning pediatric patients to adult care clinicians. Although the theoretical process for transitioning these patients may be well understood, the reality of transitioning patients with complex health care needs is in fact a much more difficult process than transitioning otherwise healthy patients. Not only is finding a new primary care clinician extremely difficult, coordinating transition for all other specialists, therapies, and routine procedures is as well. Expecting families to tackle all of this on their own is neither realistic nor patient centered. At the same time, the amount of time and energy it takes for a clinician to do this, even with the assistance of care coordinators, can be daunting. This article and case discussion present the realities of an extremely complex pediatric patient and the lessons learned through the process of transitioning her to an adult clinician from the perspectives of her primary care pediatrician (Dr Sheldon Berkowitz) and her mother (Pat Lang).

CASE DISCUSSION

Maddie is a patient with complex health care needs, all of which resulted from a history of pediatric- and infantile-onset metachromatic leukodystrophy, for which she underwent 2 bone marrow transplants in 2001 and 2002. Dr Berkowitz assumed her care when she was ∼15.5 years old and served as her primary care physician until transition occurred to an adult clinician when she was 21 years old. At the time of transition, her medical history included 30 past and current medical problems, 15 different surgical procedures, 48 medications (both scheduled and as needed), 15 pieces of medical equipment used regularly, and 15 different subspecialists whom she saw either on a scheduled or as-needed basis.

DR BERKOWITZ

When I saw Maddie for a comprehensive visit at ∼18 years old, I discussed with her and her mother, Pat, the need to start planning for transition to an adult clinician within the next year or so. As recommended by the American Academy of Pediatrics, the standard process in our hospital (with some exceptions [eg, adult patients with congenital heart disease]) is that transition occurs by the time the patient reaches age 21 years. We had previously discussed transition issues, such as establishing legal guardianship (which Pat was already in the process of completing) and making sure that Maddie had ongoing health insurance coverage after age 18 years. Helping Maddie assume responsibility for her ongoing health care needs was not a realistic expectation because of her medical complexity and physical limitations. Pat had indicated that she had no real intention of transitioning her daughter away from our clinic and hospital for many reasons, including insurance

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Dr Berkowitz conceptualized and designed the article, drafted the initial manuscript, and reviewed and revised the manuscript; Ms Lang added her own perspective for the article, reviewed multiple drafts, and reviewed the final manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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coverage and lack of comparable care options involving doctors who understood Maddie’s rare disease and care needs and had the skill sets to handle them.

At Maddie’s comprehensive visit at age 19.25 years, her mother informed me that the guardianship process was complete and insurance was in place for the time being. I again broached the subject of Maddie’s transition to adult clinicians. Although Pat made it clear that she was not interested in having that discussion for the reasons mentioned above, I explained that it was necessary and we would discuss a viable plan at Maddie’s next annual visit.

After various visits as needed related to the patient being hospitalized during the year, Maddie came back to see me a little over one year later for her comprehensive annual examination. At this point, Maddie was 20.5 years old, and her mother was willing to discuss transitioning her to adult clinicians. She shared that the family was considering a move to a different state, where they had other family supports. I volunteered to start reaching out to try to find adult clinicians who were willing to take this patient on as their primary patient in our area as well as in the state Maddie’s mother was considering.

Over the next 9 months, I worked with Pat on the transition process. Because of her complex needs, especially being both tracheostomy and ventilator dependent as well as nonverbal and only weighing ~22 kg, finding an adult clinician to take on her care was not easy. Ultimately, Pat requested that I find a clinician in a health care system in our area, through which Maddie had previously received care. This took several more months and many discussions with a new internist, who ultimately agreed to be Maddie’s primary care clinician. I also had to contact all Maddie’s current subspecialists to determine who would continue to manage her and in which cases we would need to transition her to a new subspecialist.

Finally, at the age of 21 years and 2 months, I saw Maddie in the clinic for a final visit and to transition her care. Both her mother and I spent a good part of that visit reminiscing about the past 10 years and talking about the future for both Maddie and her mother. Of the 9 pediatric subspecialists whom Maddie saw on a regular basis, 4 were willing to continue to manage her even after she transitioned; the others recommended having her seen by an adult subspecialist in their field. Copies of the most recent visit records were sent along to her new physician along with my assurances that I would be available for any questions that arose during the transition process.

Unfortunately, despite all the careful work that had gone into transitioning this patient, her care in the new system did not go smoothly over the next several months. Pat expressed the feeling that she and her daughter had been abandoned by me and our health care system.

**PAT LANG**

Complex care medical transition means different things to different people. I appreciate the opportunity to share my perspective as the mother of a medically complex child who has been living the experience. My daughter, Maddie, has a rare, genetic, pediatric-onset disease. She has had 2 bone marrow transplants, is feeding-tube dependent, is trached and vented, has a ventriculoperitoneal shunt, has had spinal fusion, and has outlived her life expectancy. She is 100% tube fed, and all her medications are administered through her gastrojejunostomy tube. I am so grateful to the medical professionals on Maddie’s team who have been loving her and helping her make it to age 22 years.

That being said, this transition process has been the most traumatic, devastating ordeal of our 20-year journey. It is like being sent on a trip against your will and better judgment with no map or global positioning system and no place to stay when you have reached the journey’s end. Once there, you find out that all the inhabitants of this new place speak a different language and have not been given the knowledge or skills to keep us alive or even make us feel safe. It is a place where policy and standard procedure seem to be more important than “first do no harm.” It is a place that is not ready for our relocation and one where no one seems to have a workable, patient-centered plan in mind to fix that.

For example, after several years of trying, I am still unable to find an adult gastroenterologist doctor who knows anything about handling gastrojejunostomy tube needs or who wants to take on Maddie’s care. I am well connected statewide to the metachromatic leukodystrophy community, and I know that the adult onset of this disease is totally different and that those patients have distinctly different medical needs. My hesitancy to transition Maddie to adult care has always been due to my uncertainty regarding whether the adult care system is prepared to handle her needs.

**DR BERKOWITZ**

Among the more difficult and unanticipated problems we encountered was determining who would arrange for routine replacements of the patient’s gastrojejunostomy tube. I learned that most adult gastroenterologists do not use or manage gastrojejunostomy tubes, and it was difficult to figure out who would replace the tube when needed. Previously, it had been replaced.
within our radiology department. Although we had been told that, in her new health care system, adult interventional radiologists would be willing to replace the tube when necessary, this turned out to be incorrect. Unfortunately, her family has yet to find a doctor or process for managing and replacing Maddie’s gastrojejunostomy tube.

**PROCESS ISSUES**

In our hospital-based general pediatric clinics, we care for ~1000 patients with complex health care needs. Because I have worked in this clinic for >18 years, many of my patients with complex health care needs have either reached the age when they needed to be transitioned to an adult clinician or are rapidly approaching that age. Ten years ago, after we had started our medical home program for these complex patients, we realized that setting up a process for transitioning them to adult care needed to be considered in a more comprehensive way. As a result, we developed our own road map (Supplemental Information) to help both families and clinicians transition older pediatric patients to adult care. Generally, if an older adolescent or young adult has minimal health care needs, transition can be simple and straightforward. Obviously, the more complex medical needs the patient has, the more difficult that transition may be and the more time will be needed to develop a workable plan for transition.

My own process has always been to start the process a couple of years before the transition will take place and ultimately do “warm” handoffs: I find a new clinician to be the primary care clinician that will meet the needs of both the patient and parent(s) and then talk to that clinician to make sure they are willing and have the skill set to assume care of the patient. Over the years, I have learned that some adult subspecialists do not have the skill set to meet the needs of soon-to-be ex-pediatric patients with complex health care needs. However, ascertaining that before transition to a new primary care clinician can be difficult.

Although some of our patients with complex health care needs can be transitioned to family practitioners (eg, patients with trisomy 21 or autism who do not have >1 or 2 other health care problems), most require the additional expertise that an internist or an internal medicine and/or pediatric-trained physician can provide. However, as has been written about previously, not all adult clinicians feel appropriately trained or medically equipped to handle some of the more complex problems that our patients have (eg, chromosomal and other congenital anomalies). In addition, they often do not have the other necessary resources in their clinics, such as social workers and nutritionists, nor do they have the amount of time needed to see these patients. Altogether, these issues describe the foundational difficulties that arise in trying to find clinicians who are willing to care for the most complex patients.

**LESSONS LEARNED**

Some of what we learned was known before we started the process of transitioning Maddie. Starting early discussions with families about the need to transition their young adults at a certain point away from our children’s hospital and giving the families (and patients, if they are able to participate) the time needed to adjust to this new reality is crucial. Finding the appropriate new clinicians to take on a patient’s care and having warm handoffs, rather than simply telling the family to find their own new clinicians and wishing them well, is essential. Making oneself available to the new clinicians to assist with any questions raised by the patient, family, and/or new clinicians is extremely helpful.

Even with the amount of effort put into this situation, what was not known when we started is how many problems could not be anticipated. Making sure that the receiving adult primary care clinician was able, and not just willing, to care for a patient with complex needs is important. Making sure that the new primary care clinician is going to be able to work with the family to navigate new outpatient, emergency department, and inpatient processes will help the transition go more smoothly. The same thing goes for outpatient rehabilitation services. Knowing whether there will be care coordinators in the new system whom you can put in touch with the existing care coordinators (if there are any) will provide some comfort to the family in knowing they will have assistance going forward.

As a pediatrician, I have not been trained in having difficult discussions with families about why it is essential to transition their young adults to a clinician who specializes in adult problems and to an adult hospital system that has the resources that are necessary for caring for their young adults as they continue to age nor in explaining that a children’s hospital has limited resources and a limited number of beds available to care for all pediatric patients in the area. But these are important discussions to have, for families, providers, and health care systems. This case, and similar ones in our institution, have prompted our hospital to look at our transition process, identify areas for improvement, and clarify the reasons behind a policy requiring transition at a certain age.

**PAT LANG**

New medical procedures are helping our children live longer, yet there are no plans in place for their future
health care needs. A physician’s job should not end because patients are aging out of a system that has extended their life expectancy in the first place. Frankly, that is like a parent telling their 18-year-old child that their job is done now because they are an adult and parental responsibilities are over. We all know that is not realistic for families nor desirable for society. Parents work hard to handle the financial burden of health care costs, coordinate care, and keep their emotions in check. Now, they have another high hurdle to jump because they are expected to navigate care coordination in a new system by themselves, all the while figuring out how to pay for it.

It is hard not to wonder whether medical professionals are oblivious to the needs of these patients or are afraid to advocate for their patients’ specific needs in a system that does not recognize this as an immediate and dangerous issue. There are some states that have clinics for our kids and adolescents. They have found a way to make it work. They surely have best practices and lessons learned that they would be willing to share with any team that is determined to make the changes needed here. In addition, it would be helpful if medical school and residency programs for internal medicine, family practice, and internal medicine and/or pediatric programs could include curricula about caring for patients like Maddie when they transition to adult care as well as adding job shadowing with clinicians who provide this type of care in adult settings.

**DR BERKOWITZ**

Our improvement process is ongoing at this time. This same concept is being discussed in the pediatrics literature. I have also started looking to the American Academy of Pediatrics as well as state medical associations to see if conversations can be initiated between pediatric and adult clinicians, both primary care and specialty care, to learn what is needed to make more adult clinicians comfortable in caring for these young adults with complex needs.

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Transitioning Patients With Complex Health Care Needs to Adult Practices: Theory Versus Reality

Sheldon Berkowitz and Pat Lang

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