

What adult rheumatologists can do for pediatric rheumatologists

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I sometimes hear that if pediatric rheumatology, as a subspecialty, needs support and help in our efforts to grow and mature (and we do!), we should rely on our internist rheumatology colleagues and organizations. This idea may be in contrast to seeking advice and support within our pediatric departments and organizations. I agree that there is much our adult rheumatology friends and allies can help us with. I also believe that our pediatric partners and administration can equally provide us with financial support, grant advice and partnership, career direction, section growth, and patients. We need both pediatricians and internists. Let's be clear. Rheumatologists are neither our savior nor our nemesis. As one of my medicine-pediatric colleagues has told me, like first cousins we may not like each other all the time, but we can try to get along. We will make it largely on our own. But we can learn from our adult rheumatology colleagues who have been at it longer and seek and hopefully receive help from them.

An adult rheumatology friend asks what adult rheumatologists can do for us. I start thinking. I can easily pick out 5 ways for adult rheumatologists to help us.

- 1) Help develop pediatric rheumatology sections in each medical center and medical school with collegial cross-fertilization and mentoring of pediatric rheumatology lab and clinical researchers.
- 2) Recognize that pediatric rheumatologists bring a crucial education component to medical schools that adult rheumatologists cannot bring.
- 3) Include transition issues and experience in internal medicine curricula and ambulatory experience.
- 4) Treat pediatric rheumatologists as true partners and equals.
- 5) Give us all the children with rheumatic disease from 0-18 years and remove pediatrics from the adult rheumatology curriculum.

My friend asks that I explain my requests.

1) Program development

The first step to developing a strong pediatric rheumatology section is to have support from both the pediatric department and the adult rheumatology section. Each should recognize that having a strong pediatric rheumatology section is essential to their missions. That is not always an easy sell. It is not optimal to have either the pediatric department or a rheumatology section try to cover pediatric rheumatology. In pediatrics, it's not unusual to try to cover parts of rheumatology with an infectious disease, nephrology, allergy, or other

specialties. It just doesn't work. The kids with rheumatic disease usually get second class care and there is often little effort to teach rheumatologic and musculoskeletal topics. No effort is made to establish a center for children with these problems.

Similarly, if a rheumatology section tries to provide the pediatric rheumatology care, the rheumatologist is often undertrained and suffers from the handicap of being an internist trying to do a pediatrician's job. The number of adult patients can make it hard for the rheumatologist to give the children the necessary time. The adult rheumatologists can not often provide the team care that is state of the art in pediatric rheumatology and other pediatric chronic diseases subspecialties. This type of care is not as available in adult rheumatology clinics and private offices. In my opinion, it is preferable if both pediatric departments and rheumatology sections commit to building a strong, academically viable pediatric rheumatology section at each medical school and major medical center, one with both research and clinical strengths.

2) Education in pediatric rheumatology

It is important to emphasize the crucial role of education. This is a role that adult rheumatologists usually cannot and do not perform in pediatric departments and medical centers. They just have too much to do. As discussed previously in this column, musculoskeletal exam skills are not being consistently taught in many medical schools. The skills in examining a child for musculoskeletal (msk) disease are a bit different than those for adults. This teaching of the pediatric msk exam is an important role for a pediatric rheumatologist in a cooperative effort with orthopedics, sports medicine, and podiatry. The exam should be a regular part of a medical school pediatric clerkship. This musculoskeletal area of pediatrics has not been focused on in the past and continues to need reemphasis in this time of decreasing resident hours, less time in outpatient clinics, and hospitalist and ICU character of many pediatric training programs.

The education of pediatric students and residents requires that the educator put rheumatic diseases in context of the pediatric differential diagnoses, growth and development, school issues, dealing with parents of children with rheumatic diseases, pediatric dosing, family dysfunction and other pediatric issues. It is often not sufficient and not standard of practice to just limit the adult rheumatology care to a child's arthritis disease. The multidisciplinary team approach is standard of care for the children we treat. This framework is not part of a rheumatologist's training and experience unless they have spent at least 6-12 months in pediatric rheumatology and a continuity experience. In many adult rheumatology training programs, the current fellows or ones trained in the last ten years have not had more than a token pediatric experience. As noted above, any adult rheumatologist caring for pediatric patients as well as adults with rheumatic disease will be usually stretched too thin to be an adequate educator in pediatric rheumatology for the pediatric students and residents. Any pediatric

rheumatologist who fills this void can quickly demonstrate their worth in a pediatric department by showing that she/he fills an important deficit in education.

3) Including transition in the education of rheumatologists

I believe that the only way that we will consistently succeed in transitioning our kids with SLE and JIA into the adult medical home is by gradual inclusion of transition subject matter into medical school curricula, internal medicine residency training, adult rheumatology and other subspecialty fellowships. Granted, it is possible just to pick an age, e.g., 18, 19, or 20 years, and send them to the adult rheumatologists at that age no matter what. I have heard some pediatric rheumatologists advocate for that approach. I do not favor that approach with many of our patients as they are often not ready for the adult care system and how to accomplish a soft landing in transition is the last thing from their minds. The adult care system is a different universe with a different approach to caring for adolescents and young adults, one that puts the onus of the care on the patient. That often does not work initially with chronically ill teens.

We favor seeking a soft landing for a difficult teen or young adult with an approach that depends more on developmental age and maturation rather than chronological age. Many of us like to mutually pick the time for transition and if possible, work with an adult rheumatologist (optimally a dual-boarded medicine-pediatric rheumatologist) in a transition clinic or informally where the shift of care is very gradual and safer. We favor sharing the responsibilities for care for awhile rather than an abrupt transition. These issues on transition issues of education, independence and responsibility, vocation, living environment, and navigating the adult care system can be discussed and taught in these transition seminars or courses. There is precedent for cooperative efforts such as in cystic fibrosis and sickle cell anemia as well rheumatology clinics.

We can work on transitioning the adolescents sooner than we currently do. We can help them develop better transition skills in education, independence and responsibility for their own treatment, vocation, sexuality, and the other skills noted above. They should not go into the adult rheumatology world utterly dependent on the pediatric rheumatology team and unable to fend for themselves. We must do better at transition preparation and ask adult rheumatologists to understand the process better and work with us. It's a two way street. Equally as important is task of finding a primary care physician for the transitioning adolescent, particularly one with a special interest in chronic disease.

We may have our work cut out for us with older, more experienced rheumatologists who may have no interest in transition issues and may think that it's more a problem of the pediatric rheumatologist. I expect that they may see us as being reluctant to let go of our patient (sometimes it is hard) or that we may not sufficiently respect the rheumatologist's ability to take care of this patient. It is possible that the adult rheumatologists may consider that they have a greater knowledge and

experience with lupus and chronic arthritis than pediatric rheumatologists. They may see this reluctance to transfer the patient's care as odd at best, and at even a bit insulting. Most have seen older teenagers as new patients and do not see much a difference in taking a 19 year with SLE who has had gradually increasing problems for 7 years and seeing a 19 year old new patient. As we have discussed earlier in this column, these transitioned patients appear to me to be at increased risk in the first year after transition before the adult rheumatologist knows them well.

How to get this topic into educational programs for students, residents, and fellows? I believe that we have to work together with other pediatric subspecialties through the American Academy of Pediatrics (e.g., the Committee of Disabilities in Children of the AAP) and other pediatric organizations. The consensus statement *Health Care Transitions for Young Adults with Special Health Care Needs* published in Pediatrics in 2002 provides some guidance. Other groups would include parent groups (e.g., Family Voices), governmental agencies (e.g., Maternal and Child Health Bureau), and transition advocacy groups (e.g., Adolescent Health Transition Project, Health care Transitions-Institute for Child Health Policy, National Collaborative on Workforce and Disability and others). Together pressure can be brought on the medical school organizations (such as the American Association of Medical Colleges) to include this important topic in pediatric and internal medicine curricula for all levels of trainees. We cannot expect to easily make transition a high priority with the adult rheumatologists by ourselves but only within a broad, consumer-driven coalition.

4) Treat pediatric rheumatologists as equals

In my career, I have had adult rheumatologists treat me respectfully and as an equal as a medical colleague and a number become good friends. I have met others who are happy to have us care for children and adolescents and leave adults to them. I recall others who were a bit condescending. Those adult rheumatologists seemed to see pediatric rheumatologists as rare, beside the point, and off their radar. This view may seem like sour-grapes but in my opinion, in many centers it is often a day-to-day reality. As I have seen such condescension from other internists who appear to believe that caring for adults is more important than caring for children (maybe not their own, but children in general). The manpower issues of the last 10 years have not helped (Pediatric rheumatology is a dying subspecialty-weren't those great headlines!).

I believe that adult rheumatologists need to consider seriously that children and adolescents with rheumatic diseases may have different diseases or disease subsets from those of adults. Clearly JIA, juvenile dermatomyositis, local scleroderma, Kawasaki's disease, Henoch-Schonlein purpura, and rheumatic fever are different than the diseases commonly seen in adults. Although SLE, vasculitic diseases, and sarcoidosis in the first 18 years of life may appear superficially to be similar or even identical to their adult counterparts, I would argue that the host organism of children and adolescents is so

different biologically, developmentally, and socially from adults that the disease subsets have major differences.

Adult rheumatologists clearly think otherwise as there are rheumatology clinics in many cities and countries for lupus or vasculitis diseases that take patients in the second decade or heaven forbid, the first decade of life. Many adult rheumatologists may see children and adolescents for the family's convenience, due to insurance issues or for variety in their practice. These are my opinions based upon experience and observation, not evidence-based medicine. I see many lupus patients in south Chicago who clearly have a very different lupus disease than many adult lupus patients. These differences may be more striking in different regions, countries, and ethnic groups. I believe that this hypothesis needs recognition from adult rheumatology and testing by both subspecialties.

It is possible to make the argument that we as a subspecialty do not deserve equal status. We are younger as a subspecialty. We have 1/10 of the workforce as adult rheumatology and have medical schools and countries that don't even have pediatric rheumatologists. We do not have enough bench and clinical researchers and lack sufficient funding for research and fellowship training. We often have trouble getting any funding from pharmaceutical companies in our educational endeavors. But if rheumatologists care at all about children with arthritis diseases, they will support us and treat us as equal colleagues. So if the rheumatologists want to help us, an important step is to treat us as allies and colleagues consistently and across the board. They can help us grow both as rheumatologists and pediatricians.

5) Adult rheumatologists should give up kids

This may sound radical. Adult rheumatologists who spend less than 25% of time seeing children and adolescents under 18 years should definitely consider letting pediatric rheumatologists and our resource physicians (pediatricians and rheumatologists who see kids greater than 25% of their practice) care for children and adolescents with rheumatic disease. Sound far-fetched, even suicidal? Let's look at this issue.

Manpower issues:

The average age for members of the American College of Rheumatology (ACR) in the US is 54 years old, reflecting a likely manpower deficit. There are not enough adult rheumatologists in most other countries and regions to deal with adults much less children. Thus there are plenty of patients over 20 years old for adult rheumatologists. Though it may be at times economically useful to see kids, I believe that ultimately adult rheumatologists can do just fine seeing adults only.

Training

Most adult rheumatologists do not train extensively in pediatric rheumatology (>6 months) and often had only 1-2 months at best. They are internists first of all and may not have acquired the pediatric skills important for caring for young children, especially infants, and even adolescents. Rheumatologists especially do not often get a continuity experience with children. They may come to 8-10 pediatric rheumatology clinics, study hard to

answer questions on the rheumatology certification or board exam, and then if they pass they are now supposed to be qualified to take care of children with rheumatic disease. The truth is that they do not have the experience or the skills to care for these children. The adult experience and skills obtained in fellowship does not transfer to pediatric rheumatology (You know the saying, kids are not little adults). In order to be properly trained in pediatric rheumatology, a rheumatology fellow should experience either a consecutive 6 months of pediatric rheumatology with inpatient responsibilities or a twice a month pediatric rheumatology continuity clinic throughout their training with an additional three months of inpatient consultations.

Without this training, rheumatologists will know little about school issues, transition, pediatric dosing, pain issues in kids, dealing with parents (often quite different than dealing with adult patients and their families), and normal growth and development as it relates to chronic rheumatic diseases. It might be thought that the child's pediatrician may take care of these issues. But there are problems with that assumption. Many teens do see their pediatrician only occasionally and the pediatrician may not be comfortable with the rheumatologic disease and chronic illness. As much as the medical home concept is advocated in the US, it will be awhile before pediatricians learn enough about rheumatic disease in their residency to be comfortable with these special chronic disease issues of our children. It is very easy for these problems to fall between the cracks.

Diseases

Are rheumatic diseases the same in the first two decades? As mentioned above, I would suggest to you that kids are different hosts than adults and the diseases and disease subsets are different. Including children in an adult rheumatology practice mixes apples and oranges and the tendency may be to approach these patients with the same practice guidelines as adults. For example, I have observed many children with chronic arthritis over the years that have been undertreated by rheumatologists. Granted we don't always see the denominator patients who do well but we do see a number of children for second opinions who have not been given aggressive medications by rheumatologists because they do not complain of pain and appear functional. Children and adults can be very different as patients to make carry-over from adult care to pediatric care risky.

Consequences-good and bad

You may be shaking your head and thinking that if pediatric rheumatologists start caring for children that adult rheumatologists now treat, we will be inundated and swamped with patients. Yes, we will in some countries for a short time. But we can adjust and adapt. We can shift our practices to see more of the serious and severe rheumatic diseases in children and educate pediatricians to take care of children with positive ANA's, mild musculoskeletal pain, mild oligoarticular JIA, and iritis rule out disease, persistent HSP, and Kawasaki disease. We will see the kids we went into pediatric rheumatology to treat. We will have more children who need acute hospitalization and rehabilitation stays. We can show the

administrators and chairpersons that we indeed have a lot of patients and many with severe disease. The increase in morbidity in our patients will provide more justification for more faculty hiring, fellow training, research projects for CARRA, and money for more support personnel and research. We may displace more “academic water” in our pediatric departments and gain more respect. We will enjoy getting up out of bed each morning even more.

I believe that the current rheumatology system is broken and dysfunctional. It does not provide the best care for children. It is time that adult rheumatologists focus on the numerous adults with rheumatic disease and basically refuse to see any patients under 18 years old and refer them to pediatric rheumatologists. Let’s face it; there is a standard of care issue. There is no way that adult rheumatologists can provide the care that a pediatric rheumatologist can due to their lack of training in pediatrics and pediatric rheumatology. The decisions of insurance companies to send patients to an adult rheumatologist over a pediatric rheumatologist are penny-wise and pound-foolish

Though most countries have pediatric rheumatology workforce deficits, it hinders our growth as a subspecialty rather than helps us that rheumatologists see children and adolescents. We can only grow and provide children with the best care if we see all the patients between 0-18 years. Like every rule, there may be exceptions. Children who live more than 150 miles from us may see an adult rheumatologist regularly but still see a pediatric rheumatologist every six months for added brainstorming and input. Countries without any pediatric rheumatologist or with very few pediatric rheumatologists must await the time when one or more pediatric rheumatologists start and in the meantime utilize rheumatologists resources. These are temporary solutions until there are enough pediatric rheumatologists to service urban and rural areas of the US and other countries. Adult rheumatologists who spend more than 25% of their time seeing kids with rheumatic diseases are an important resource; they should continue to see children unless there is a pediatric rheumatologist who can care for the same population. Lastly, adult rheumatologists who live close to pediatric rheumatologists (within 150 miles) should particularly refer the children and adolescents and focus on adults.

Summary

My friend said he would speak to the powers that be at the ACR and Arthritis Foundation. If adult rheumatologists want to help us and the special patients we care for, it is time to increase their assistance and support in the development of our pediatric rheumatology sections, understand our educational mission, include transition in trainee education, consider us by word and deed to be their equals, and focus on adults and leave children and adolescents to pediatric rheumatologists. Adult rheumatology is in a stronger position as a subspecialty. They are older, more developed, wealthier, and more accomplished. I believe that they can afford to be generous.