A Common Thread: Pediatric Advocacy Training

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“There wasn’t any insulin left at home, so I skipped a day or two,” Erika explained. The thin teenage girl sat tucked between white hospital linens. Two days earlier, she had been rushed to the emergency department by ambulance after a neighbor found her unconscious at a park near her home. The routine of stabilization and correction of electrolyte abnormalities went smoothly, just like it had on her several previous ICU admissions. She was lucky to be alive, yet again.

Each of Erika’s past admissions for diabetic ketoacidosis (DKA) had started with the same story: not checking her blood sugars, and not taking all of her insulin. Erika’s explanations were always guarded, only hinting at her difficult reality. Her mother, an undocumented immigrant raising 4 daughters on her own, worked 2 jobs to keep the family afloat. They often could not afford the fresh foods that Erika’s doctors recommended, much less all of her insulin and glucometer supplies. They frequently missed appointments because they did not have the money for transportation to clinic, or because her mother could not take time off work for fear of losing her job.

Although they wanted to help, Erika’s medical team was left managing her health by a strategy of intermittent crisis intervention. Erika’s nurses and diabetes educator reminded her of the importance of home glucose monitoring; her social worker reviewed her paperwork for Medicaid and food stamps; her pediatric endocrinologist scheduled a follow-up appointment to evaluate her diabetes management and reinforced the health risks associated with DKA. The team worked diligently, but ultimately Erika was discharged from the hospital to face the same obstacles that had repeatedly landed her in the hospital.

As trainees, we are taught how to manage DKA. We know which laboratory studies to order, what fluids to run, and how much insulin to give. Stabilizing sick children is the bread and butter of inpatient care. Yet when faced with children who are repeatedly hospitalized with preventable illnesses, we often feel powerless to stem the flow. Many of us will complete our training without a strong understanding of how to advocate for patients like Erika. In fact, many of us may lack a full understanding of what exactly advocacy means. Our medical education should provide the training and resources necessary to prepare each of us to advocate for our patients.

At the heart of it, advocacy is about endorsing effective solutions. Advocacy can happen on many different levels, ranging from developing community-based resources to lobbying at the national level. Pediatric graduate medical education continues to evolve in an effort to empower the next generation of trainees with the skills needed to advocate for meaningful societal change. The Accreditation Council for Graduate Medical Education has mandated that all pediatric residency programs’ curricula must “include elements of community pediatric and child advocacy.” As a result, medical schools and residency programs are increasingly adopting advocacy and service-learning curricula that include community resource identification and referral.

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screening for social determinants of health, effective use of medical-legal partnerships, and political engagement.3–6 Furthermore, some institutions are piloting innovative curricula in an ongoing effort to develop the most effective method to teach trainees the art of advocacy.7,8 The American Academy of Pediatrics (AAP) has also taken deliberate steps to encourage trainee involvement in advocacy initiatives. Trainees are invited to collaborate in the AAP’s fight against child poverty by participating in the AAP Section on Medical Students, Residents, and Fellowship Trainees (SOMSRFT) 2015 advocacy campaign, “F.A.C.E. Poverty: Food Security, Access, Community, Education,” which will focus on confronting the issue of child poverty at the local, state, and national levels. In addition, the AAP offers annual funding awards for trainees, including the SOMSRFT Anne E. Dyson Child Advocacy Awards as well as the Community Access to Child Health (CATCH) Resident Grants to support trainees in the planning and/or implementation of community-based child health initiatives.

Although these opportunities have yielded many successes, only a small group of physicians will dedicate their careers to advocacy on the state or national level. Yet all pediatricians and pediatric subspecialists are called to advocate for their individual patients on a daily basis. Every child deserves a physician who understands how to best advocate for his or her individual needs, whether by identifying local resources for a family; urging an insurance company to cover an important treatment, or working to ensure extra school-based services for a child who has disabilities. In the United States, a staggering 22% of children live at or below the federal poverty level, leading to increased prevalence of chronic diseases and related morbidity, food insecurity, obesity, accidental injury, and decreased access to quality health care.9,10 In the face of such overwhelming need, learning how to effectively advocate for our patients is of paramount importance for pediatricians-in-training.

Despite the efforts to provide more effective advocacy training, significant challenges remain. For example, most residency programs have adopted a 2-week block dedicated to advocacy training, modeled after the traditional structure for subspecialty rotations. However, whereas not every pediatrician will become a cardiologist or rheumatologist, every pediatrician will need to become an advocate. A 2-week “lump sum” of advocacy training is important but insufficient exposure in light of the complexity and severity of the challenges many children face. Advocacy should become a thread that weaves through all 3 years of residency training. Patient advocacy should be viewed as a core competency in every clinical setting, and opportunities for teaching and engaging in advocacy should be sought out in each rotation. Attending physicians should also continue to bolster their own understanding of advocacy, so they can serve as examples for trainees.

However, the onus of education does not lie solely with the educators. Trainees must be open to the idea that “advocacy” is not simply an accreditation requirement, an isolated community immersion experience, or a project with a definitive endpoint. We must seek opportunities to learn. For example, rather than simply ordering a social work consult, trainees could work with the social worker to better understand what happens to children after they leave the hospital. This will certainly be challenging when confronted with the heavy patient loads and busy schedules of trainees, but we have chosen to become pediatricians. With this decision comes the responsibility to provide our patients with the best chance at a healthy life. Any trained pediatrician can manage a case of DKA, but this is often patching the holes in a sinking ship. All general pediatricians and pediatric subspecialists should seek to understand the roots of their patients’ problems and work to steer the ship away from coming storms. This is the model toward which we all should strive.

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REFERENCES


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