Advocacy in pediatrics: It’s part of patient care

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ake was a five–year–old who had just been taken into foster care. I saw him at his school for developmental concerns. His mom told me that she had moved to Vancouver to escape an abusive relationship and an unhealthy lifestyle. She was looking for housing and in the meantime was “couch surfing” with various friends and acquaintances. Social services intervened and placed her son in foster care. I confirmed with the social worker that her lack of housing was considered a Child Protection issue and she was obligated to remove him. Jake was in foster care because his mom could not afford to pay rent in Vancouver. I watched him hold tightly to his mother as the social worker took him away. He cried out to his mother to let him stay with her. She silently watched him leave with tears streaming down her face.

What is the correct response for a physician in a situation where the child’s problem is caused by poverty? We collaborate with social workers that generally work to keep children with their parents, but their decisions may be shaped by factors that ultimately do not serve the child. The social worker felt helpless; the waiting list for social housing was many months, and her supervisor insisted that children must have stable housing to be safe. We went to the local Member of the Legislative Assembly’s office, called various agencies, and made no progress. With the mother’s permission, I called the newspaper and they ran a story. The next day they were placed in housing and strangers sent them money to help them get back on their feet.

Rachel Remen, a great pediatrician, said: The meaning of medicine is not science; it is service. It is not a competency; it is a way of life, the deep wish to make things better or larger than how you found them. Service is larger and older than science.

I started my career as a Pediatric Emergency Physician. One night, three in the morning, I saw an eight–month–old baby in septic shock. Despite intensive efforts to save him, he died. A normal baby had just died of a completely treatable condition in a major teaching hospital in a country with universal health care. I slowly walked into the waiting room to tell his young First Nations parents that their child was dead. The mother told me how they had come to emergency earlier that day and were told that he likely had a virus, but to bring him back if he worsened. When he became lethargic, she called, but interpreted the advice as being that bringing him back was an abuse of emergency services. She didn’t have the courage to bring him in before it was too late.

I am not a political person; I am just a pediatrician. I see children and families and try to help by listening, diagnosing, recommending treatment, and mostly by creating a safe place where parents and children can confide their deepest concerns and fears. Over the years, I realized that many of the issues I was seeing needed to be dealt with at a higher/broader level than a pediatrician’s office.

We are in an era of pediatrics where prevention and treatment for many conditions that caused morbidity and mortality for children in previous generations has been achieved. Physicians caring for children are increasingly faced with health issues that are caused by poverty and other social vulnerabilities. If you are a physician seeing children today, you are seeing the results of toxic stress. In BC, one out of five children are living in poverty. Eradicating the root cause of many of their health conditions involves identifying poverty as the cause and advocating for social change to prevent its effects. Once it was determined that polio caused significant childhood morbidity, physicians advocated for a universal vaccine to eradicate it.

For children in poverty, standard medical care is often just a patch job for the underlying problem. As pediatricians, we are the experts; we must speak out about factors that prevent children from reaching their potential. Advocacy comes in many forms; it can be as simple as asking parents about food security and early adverse experiences; it can involve writing letters to newspapers, calling school principals, speaking at community meetings and medical conferences. Being a physician gives us a voice that people listen to; with that power comes an obligation to use it.

I started a charity, Mom to Mom, where I could put my knowledge into action. Volunteers are trained as mentors to work with moms who have experienced generational poverty to provide friendship and support for basic needs like housing and nutrition. The volunteers provide the kind of support that middle class mothers get from their network of friends and family. Women living in poverty may have supportive families, but they are often facing the same challenges that their mothers did. The more I spoke out about what I was seeing, the more support Mom to Mom received. Support came in the form of money for families, action at schools, and recognition of the challenges that families in poverty face by citizens who were unaware of what was happening to children in their province.

There were also barriers; I was shocked when hospital administrators told me to stop advocating, that it was unethical to be a physician serving vulnerable children and to also speak out for policies that affect them. They said that the provincial government might feel criticized, which could adversely affect hospital funding. University and hospital ethics boards advised me to continue. Advocacy for children is not a partisan activity; we advocate for children and their basic rights to health, education, safety, and recreation. I insist in the same way that I would persist in advocating for a child to get antibiotics for meningitis. To not do so would be unethical.

There has been debate as to whether it is our job to advocate for patients. From my perspective, advocacy is a form of patient care. We see patients and determine the best treatment. It may be a medication, a call to a social worker to ask for food, or a letter to a school to ask for supports. We see what children need and advocate for it. Children do not have a public voice; we can and must be that for them.

Advocacy is also good for physicians. We entered medicine to help people; when we are unable, we feel frustrated. Speaking up allows us to provide patient care. I have recently written that poverty may be the diagnosis in many conditions that we treat and call other things. When we see a way to change the life of a child, how can we keep silent?

References


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