Pediatric Clinicians and Parents: Working Together for the Benefit of the Child

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EDITOR'S NOTE:

Mark Schuster gave the Academic Pediatric Association Presidential Address in April 2015. During the session in which it was given, his speech followed several presentations that touched on communication with families and that are referenced in the speech. We reprint his remarks here.

MY FIRST RESEARCH project landed me in court. I was a doctoral student and read a newspaper article about a high school condom availability program starting in a local school district. This was a novel, even shocking, idea in 1992, so I asked the school board if I could evaluate the program. They said yes, and I designed a pre–post survey study that covered sexual behaviors that the program sought to influence. Every concept and word in the survey was in the district's 9th grade health curriculum. Many parents welcomed the program, but some parents, not surprisingly, objected to baskets of condoms scattered around the school. They weren't able to stop the program, but our study was an easier target and became the focal point for efforts to undermine the whole thing. A small group of parents organized protests outside the building where I worked. One parent got himself on the evening news by saying that our survey asked questions that no high school student should ever see, and then he proceeded to read one of them on the air so that children of any age could hear it. Things got so crazy that we had to contend with claims that we were holding kids hostage around California and forcing them to take our survey. In a last-ditch effort to stop the study, the organizers took us and the school district to court, which involved a lot of effort, a lot of time, a lot of money, and a lot of nail-biting. The principal and superintendent stood firmly in support of the study. Many parents rallied in defense of the study, pointing out the desperate need for information on the current generation of adolescents. We prevailed in court, and in the end, our study moved forward, bruised but not beaten. I was able to report back to the district that half of students had taken condoms, many had used them for sexual activity, and others had taken them out of the packet and explored how to use them.

What struck me most about this ordeal was how strongly parents on both sides of this battle felt. At heart, I think that everyone involved really believed they were advocating for what was right for these adolescents. Yet they had such opposing views. They looked at the same facts, the same circumstances, the same group of students, but they disagreed passionately on what was best for those students.

There was one thing, though, that everyone did agree on—that parents needed more support in addressing their children's sexual health. At that time, what had been missing from efforts to prevent HIV, other sexually transmitted infections, and unintended pregnancies was parents. No one cared about these kids more than their parents did, and yet strategies to reach kids back then generally worked around parents rather than with them. This realization prompted my first major study as a faculty member, to develop and evaluate a program to help parents address their children's sexual health. Instead of telling parents what to think or what to teach their kids, we helped parents build skills to start conversations, explain basic facts, impart values, and deal with complex situations. Taking a similar approach, a med school friend and I wrote a book, *Everything You Never Wanted Your Kids to Know About Sex (But Were Afraid They'd Ask)*. It aimed to give parents tools to decide what to teach their kids and how to do it. I should say from the start that I'm using the term "parent" broadly, to include anyone functioning in that role.

Over time, my work in academic pediatrics moved beyond helping parents address their children's sexual health to helping them address their children's health in general. This has involved listening to parents, exploring what assistance they'd like from clinicians, and thinking about ways in which our profession can best meet their needs. My focus today is how we can provide parents with the help they need to take an active role, a leadership role, in seeking the best health outcomes for their children, consistent with their values and beliefs. To do so, I believe we need to embrace the emerging concepts embodied in patient engagement—or rather, family engagement.

Most recently, I have been studying family experience of care, culminating in the development, with Sara Toomey, of the Child Hospital Consumer Assessment of Healthcare Providers and Systems Survey, or Child HCAHPS. That's a mouthful, but in plain English, Child HCAHPS is a survey that gives parents a voice to report on their children's and their own experiences in pediatric inpatient settings. It asks questions like, "Before your child left the hospital, did a provider ask you if you had any concerns about whether your child was ready to leave?" Through focus groups, interviews, and our national field test in 69 hospitals, I've had a chance to see how parents feel they're treated by clinicians, to hear their stories and learn their frustrations.

Parents told us they want to be treated with respect, kept informed, listened to. They want to be able to ask questions. They want a voice. There were a number of positive reports, but many parents felt excluded and overlooked. As one parent explained, "I think that some of the nurses, I don't know, maybe because they have a lot going on, they tend to get mad when you ask questions. But before you do anything to my child, before you give him anything, I feel I need to know what it is." Another parent said, "You get the residents that are coming in and rotating through, they've all got [a] chip on their shoulder like, 'We know more than you because we're doctors.' And I'm like, 'Yeah, but I'm the parent and I know my kid better than you do.' … They're like, 'I'm the doctor!' and I'm like, 'Yeah, back off. I'm the mother.'"

The role of health care providers has changed and continues to evolve. There was a time when we were the only source of health information. Sure, there were grandparents and parenting magazines and disease-of-the-week TV movies, but by and large, we were the primary means by which most parents learned about their child's major health issues. We've now entered a new era. We've all seen how the Internet and social media have changed access to information. Parents come in pointing out Web sites on their smartphones and declaring that they know their child has this diagnosis or needs that treatment. Sometimes the information is correct. Maybe a parent has stumbled onto a new treatment or a clinical trial their child might qualify for, or the information helps them better understand what we tell them. Or it may be flaky, not relevant to their child, or just plain wrong. In both cases, whether information is absolutely correct or total nonsense, we need to work with parents, support them in their search for information, and help them interpret it.

Perhaps parents resort to Internet sources because we fail to engage them sufficiently on issues they really worry about, on their fears and superstitions. This failure has been a challenge for years, but it seems to have become even more of a challenge recently. With short visits becoming rushed visits and computer screens holding our gaze, a great many pediatric clinicians haven't been communicating with parents as well as we might hope. "Here, get this shot." "Take this pill." "This piece of paper will explain it." "You don't have any questions, right? No, good." It's no surprise that some parents look for answers elsewhere.

We need to fix this. We need to encourage pediatric clinicians to build different and stronger relationships with parents if we want to do all we can to promote the best health outcomes for children. We need to take a hard look at the way we think about the role of parents in pediatrics. We need to support family engagement, which emphasizes that parents are not just repositories of children's health history or dutiful implementers of our recommendations. As clinicians, we may only see a child once or twice a year, but parents are with their children day in and day out. They ultimately determine what happens to their children—what they eat, how much they exercise, whether they have a bike helmet, or whether they take the medicine we prescribe. If parents don't meaningfully understand the health issues, treatment options, and recommendations, there is a very real risk that they may reject our advice, or just forget to execute it, and our patients may not get the care we think is best.

Family engagement focuses on the need for parents to understand and use information about their children's health, engage in shared decision making, and participate in quality assessment to improve health care. We, as clinicians, educators, researchers, and advocates, all play a key role in supporting parents in these activities. In shared decision making, parents and clinicians both provide their expertise on the child's health and express their preferences. Parents may choose to make decisions with only basic information from us, or they may want to think about issues jointly, with back-and-forth processing of the options. If we take time to understand their values and preferences—or better yet, to help them articulate their values and structure a decision—we can help parents take control of their child's health care.

Shared decision making is most relevant when multiple treatment options are supported by evidence, and the choice may vary by values and preferences. When there's a choice between treating an ear infection or watchful waiting, there's a decision to be made. For attention-deficit/hyperactivity disorder, many parents are never told about the choice among medication, behavioral therapy, or both, or that there's a decision to make about whether to transfuse now or wait to see if the hematocrit comes up on its own. They're just given the option their clinician assumes they would want. And even when there is no real choice, family engagement still has much to offer. There's a difference between saying "I'm going to do this now" and "I think we need to do this now. I'm afraid I have no other options to offer you. Here's why."

I recognize that, for the clinicians in the room, we already try, we already aspire, to engage parents in shared decision making, whether we call it that or not. I've been trained by some of you, practiced beside some of you, and taught some of you. One or two of you have even provided care to my kids. But despite our best efforts, many parents indicate that clinicians do not engage them in making health care choices. Even when we think we support shared decision making, it's not clear we really understand