In the Moment

I Had a Gun in My Purse

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When a patient walks into clinic with a blood pH less than 7, it is a memorable moment; when a patient does so over and over again, he becomes a memorable patient. So it was with Josh.

Josh was in his early teens and had lived with insulin-dependent diabetes for 5 years. He had been doing reasonably well when he suddenly began to have repeated episodes of ketoacidosis. He would be brought into the clinic pale, with tachypnea, eyes sunken, and barely able to walk or speak. We immediately started intravenous lines, began fluid and electrolyte resuscitation, sent labs, gave insulin, and called the ambulance for transport to an inpatient unit. Once his ketoacidosis was resolved, Josh stabilized with diet and insulin and his laboratory results normalized. When well, Josh was a shy, somewhat guarded, but cooperative and pleasant young man. His mother brought in a detailed daily logbook with records of his insulin doses and home blood and urine glucose measurements but could give no reason for his deterioration. For the interns and residents who took care of him, Josh was a terrifying enigma, a boy who, despite successful resuscitation, investigation, hospitalization, and education, came back repeatedly with the same severe symptoms.

Why was this happening? Some of the residents at the hospital were suspicious that Josh wasn't getting proper care at home. His mother was ever present, controlling and overbearing to family and staff alike, and demanded my input as the attending rather than the input of the residents. His father came to visit with Josh rarely, spoke infrequently, and showed little emotion. The family had moved from out of state several years before; there was reported involvement with law enforcement, though not with Child Protective Services, in their past. On rounds, we discussed involving Child Protective Services and reporting potential medical care neglect. This, however, wasn't done; instead, we concluded that Josh had "brittle" diabetes.

After repeated admissions, we knew something had to change or Josh could easily die. We decided to try intensive patient education as an outpatient. Josh came in every day for several weeks, missing school and spending most of the day in clinic. He read about diabetes, talked about diabetes, and demonstrated good diabetic self-care practices on his own and with his mother. It was part school, part detention, and part clinical diagnostic unit. Though at first sullen and bored during his visits, he soon opened up, revealed a quiet and engaging personality, and became part of the clinic for a time. Josh improved. Afterward, the hospitalizations and repeated episodes of diabetic ketoacidosis ceased.

A decade later, his mother came to me in clinic with a request; Josh was in prison and his health was worsening. His mother wanted me to testify at a court hearing regarding his further incarceration and his increasing medical needs. I told her I hadn't been his doctor for some time, but she prevailed—no one else had known him so well. I testified and educated the court about the needs and prognosis of young people with diabetes; his care improved.

Unfortunately, Josh's later outcomes have not been good. Josh has suffered many long-term consequences from his diabetes. Having long aged out of pediatrics, he is no longer seen in our clinic, but his mother sometimes accompanies her grandchildren to the clinic, and we talk about how our families have grown with the years. It was at one of these visits that we reminisced about Josh's repeated hospitalizations as a teen.

After laughing about his "diabetes education days" that almost made him a part of the staff, she turned serious. "You know, Dr Marshall, I overheard those interns and residents talking about reporting him to Child Protective Services. But I was ready. I had a gun in my purse." Shocked, I didn't know what to say. My feelings of anger, fright, and relief were mingled together, modulated by the passage of years.

Josh's mother had trusted me to the extent of valuing my input about Josh's health needs many years after he became an adult. And that trust, developed over time, yielded valuable information. In the past, when discussing families with the pediatric social worker, we have often remarked to each other that "there is more to this story." Sometimes revelations come after 1 more visit, 1 more month, several years, or never at all. These revelations told stories, in this

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All patient and personal identifiers have been removed or disguised so that the patient or persons described are not identifiable and cannot be identified through the details of the story.

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case one that resulted from something as seemingly trivial as a misunderstood doctor's remark.

In Josh's case, lack of trust had prevented us from gaining a clear understanding of why his diabetes was so out of control. Reflecting back, I see that the family was coming from a place of fear: Josh was a poor, minority child. His family had recently moved from another part of the country and had come to our county hospital clinic because it was the only option. There was a suggestion of previous trouble with law enforcement and perhaps imprisonment. In our clinic, the family saw many different residents and students and more again at the inpatient hospital. They overheard accusatory comments at odds with what was said to their face. Was it any wonder they didn't trust us? It was only after many years of care that his mother felt comfortable telling me about the gun.

As a member of the health care team, I believe that our work rounds should be open, freewheeling, and unrestrained; like our inner thoughts, they are not for patient or family listening. Child neglect and abuse, like any other life-threatening condition, has a place in the differential diagnosis of a child whose illness is not understood. Parents, however, would be full of worry and despair if they were privy to all our early discussions, especially without explanation. A breakdown in maintaining this distance while discussing Josh's care worked to everyone's detriment and could have been disastrous.

We talk to families about safety every day: car seats and sleep position in newborns, choking hazards and falls in toddlers, drugs and alcohol in teenagers, even the dangers of guns. Just a few years ago, 3 faculty members in our College of Nursing were murdered by an armed student at our own health sciences campus. I had been naïve in thinking of the hospital as an always-safe refuge for the ill and injured. I assumed that our beneficence to patients and their families is accurately perceived and would be reciprocated and acknowledged, forgetting that ours is also a profession notable for authoritarianism, elitism, and wealth. I failed to appreciate the feelings of fear, anger, and disorientation engendered by our work. Unless treating inflicted physical injury, it is easy to forget that a patient or family could turn violent; the worldview of our profession is one of healing. Usually, and happily, this is accurate, but we must remain aware of the potential for violence, especially in a national environment where guns are common. We must protect our staff and ourselves. Recognition of the profound emotional context in which we work can be impaired by the day-to-day ordinariness we may feel in our clinical work.

I still don't know exactly what was going on with Josh and his family. Probably the insulin and blood glucose records his mother brought in were false, meant to appease us or show us she cared. It seems clear his repeated episodes of severe ketoacidosis resulted from lack of patient adherence, but who was responsible will never be understood. I believe there was a potential for danger and violence in the hospital and am so thankful that nothing happened. I am left more humble about my ability to intuit family feelings and more cautious about potential workplace violence, though still cognizant that the most significant threats to my life and health in the workplace are the commute to the hospital and forgetting to wash my hands. I realize that patient adherence can be a function of trust and understanding, and that we finally gained some of that with Josh and his mother. I know each patient encounter brings the promise of clarity but also the probability that some things will be misconstrued, persistent sources of concern to me, my patients, and their families.