

BREATH

ENCOURAGING PATIENTS TO BE THEIR OWN ADVOCATES

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As I enter the room, my 3:00 patient props herself up with her cane so she can stand and shake my hand. “Doc, I’ve been doing real good with my sugars, so I knew it was time to come in.”

Charlene was probably the most difficult patient I had intern year, but she has grown on me in many ways over the past year. She’s 54 and lives alone on the south side of Pittsburgh. She once told me a story about how, on the bus ride to the hospital, the driver got in a screaming match with one of the passengers and that made her late to her appointment. I forgave her in that particular instance. Unfortunately, she misses or reschedules about half of her appointments. Struggling with obesity, chronic pain, and severe anxiety, she often has trouble making the journey in. When she does make it, she often looks at me skeptically and says, “But, doc, I have to keep eating even when I’m not hungry, you know, to feed my insulin.” It is difficult for Charlene to grasp the concept that she doesn’t need to constantly eat to prevent hypoglycemia.

Charlene normally attends our appointments in dark-colored sweat suits, waiting at least five minutes before she actually makes eye contact with me. Today, she presents herself in a colorful dress and a smile on her face. She immediately makes eye contact with me. Reviewing her chart, I notice that she had followed up with her endocrinologist as well as our diabetic educator.

“I know I have a ways to go, but I’m feelin’ good. I’m even feeding my insulin less, and I think that’s helping.”

These are big steps. I congratulate her, and together we review her glucose logs, meticulously making changes to her already-complex insulin regimen.

I ask next about her anxiety.

“I’ve been going to my women’s group every week, but, doc, I’m still worried all the time. What if I lose my insurance?”

To this, I don’t have a good answer. I can’t solve this problem as I can with her insulin. All I can do is validate her concerns.

Charlene is on Medicaid, as are about half of my patients, and she is currently on disability. As generalists, we have to accept that the greatest determinants of our patients’ health lie outside of what we were taught in medical school. Charlene’s obesity and poor control of

her diabetes all stem from significant generalized anxiety disorder, limited health literacy, and difficulty physically making it to clinic. Over the past year, she has been treated medically for anxiety, enrolled in a support group, and provided with biweekly diabetic education. She has also received transportation to clinic paid for by her insurance, which has significantly increased her attendance. By and large, our interventions are not medical; rather, they target a much broader psychosocial context. We are able to provide these interventions in Charlene’s case because of her insurance’s ability to afford them. She happens to have Medicaid, but a large portion of our patients have insurance through the Affordable Care Act (ACA).

With the ACA constantly being threatened, the need for physician advocacy has become more immediate. I shared Charlene’s story with my state senators in hopes that this will personalize that which has become so political. I also encouraged Charlene to write to them as well.

“Now that you mention it, we were talking about writing to them at my women’s group and we might do just that.”

My residency program has established a group of residents who are all starting to incorporate patient advocacy into their practice. We meet once per month and learn about how to advocate for our patients, whether it be through story telling or trips to Harrisburg to lobby for bills. By attacking this larger context, we hope to affect the medicine as well.

Charlene is finally making progress. Medicaid has allowed her to receive appropriate treatment, and it has given us as generalists the opportunity to improve her health outcome. The current political climate has created a unique opportunity—it has given rise to a new generation of physicians and patients who have become inspired to advocate for health care.

As the appointment is ending, Charlene’s Hemoglobin A1C result comes back and has come down from 8.8 to 7.6—she has not been below 8 in years.

She cheers loudly and we high five. “Doc, I am so excited!”

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