



# When the Difficult Patient Was Me

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**A**s behavioral science faculty, I've spent the last decade educating medical students and residents about topics like communication skills, empathy, and shared decision-making. Consequently, I felt I had a good handle on the physician-patient interaction. However, when faced with my own health issues, I struggled to balance advocating for myself with my concern about being perceived as difficult.

Initially, I attributed my fatigue to the circumstances surrounding COVID-19, including working from home and social distancing. My sore muscles must have been due to the packing and unpacking that accompanied relocating across the country for my new job. However, my symptoms continued to worsen. I made an appointment for a physical with a local family physician in my new city and mentioned my fatigue. She was warm, listened empathically, and added a thyroid panel to my routine bloodwork. She let me know that she was going out on maternity leave but someone else in the practice would be in touch regarding my results. The following week, I received a call from the practice family nurse practitioner (FNP) who explained that my bloodwork was normal, except for slightly elevated calcium, "Nothing to worry about. We'll check it again at next year's physical."

This may not have been a major concern for her, but I googled

"high calcium" as soon as I got off the phone. The first entry pointed to hyperparathyroidism (HPT) as the most common cause of hypercalcemia. Next, I found a list of the symptoms I'd described to my doctor along with additional ones I had also experienced but hadn't even realized might be related: brain fog, hair loss, and polyuria. I told my spouse about this condition that seemed to sum up so much of what I was experiencing.

"Tell them you want to look into it," he suggested. I hesitated, recalling a colleague's "Don't Confuse Your Google Search With My Medical Degree" coffee mug. But his next question, "Do you want to keep feeling this way for another year?" spurred me to action.

I called the family medicine office to request an appointment to discuss my high calcium. During my initial appointment, my family doc asked about my occupation, but the FNP probably didn't know that. I wondered if it would give me some sort of special privilege to mention it. I arrived armed with a summary from UpToDate (which I hoped would signal that I had some association with the medical community) and a list of my symptoms, ready to make the case for ordering a parathyroid (PTH) level and a repeat calcium. This part was easier than I'd anticipated—the FNP ordered the tests with no problem. A few days later, she called to provide a referral

to endocrinology based on my elevated calcium and PTH. I felt relieved that things were moving forward.

Several weeks later, I arrived at the endocrinologist feeling like I had a basic understanding of HPT and some of the medical risks of failing to treat it. The endocrinologist glanced at my labs and asked minimal questions. She did, however, ask, "Have you had any fractures or any kidney stones?" in a manner that seemed to convey that if I hadn't, my labs weren't really a big deal. She informed me that my levels were only slightly above normal limits, that scans likely wouldn't reveal anything yet, and that no surgeon would operate on me. I am certain the disappointment showed on my face; I wanted this fixed so I could feel better. She recommended "watchful waiting" because there was no medication for HPT. I attempted to advocate for myself, reiterating my troublesome symptoms along with my increased blood pressure. Perhaps I was reading too much into this, but she seemed exasperated by my comments and ready to end the visit. I made one last attempt, "So I should just keep feeling crummy and come back in 3 months?" She responded that she could send me for

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some imaging but, again, with my slightly elevated levels, it probably wouldn't show anything. I left with a follow-up appointment scheduled for 3 months later along with feelings of frustration, sadness, and confusion.

I ruminated for a few days, reviewed the literature again, put aside my concerns about being seen as difficult, and contacted my family medicine office. By now, the family physician with whom I'd had my initial physical had returned from maternity leave. I congratulated her on her baby, launched into my plight of feeling dismissed by the endocrinologist, and requested a referral for an endocrine surgeon. She was supportive and made the referral. I was grateful for her return and her support but apprehensive about the visit with the surgeon, expecting to have to make my case again.

Instead, at the surgeon, I was met with open-ended questions, empathy,

and shared decision-making including a clear explanation of the risks and benefits of surgery. The following week, scans revealed an adenoma, and my parathyroidectomy took place 3 weeks later. Within days of the surgery, I began feeling better and reflected on all that transpired. The need to advocate for myself across multiple providers made me defensive and caused me to consider myself difficult. Had I gone with the initial recommendation of waiting until my next annual physical to retest my calcium, I would be waiting another 7 months. Had I accepted the response of the endocrinologist, I would have had my "watchful waiting" appointment 5 weeks later. I am glad I risked being difficult.

I feel grateful to have ultimately been heard and received the care I needed, and I view this as an opportunity to educate future physicians on the importance of listening

for how their patients' chief concerns affect their lives. Unfortunately, the tenets of relationship-centered care will not fully solve this type of problem. The reality for family physicians is that the emphasis on integrating medical knowledge with humanism and compassion must be balanced with the demands of flow charts, algorithms, authorizations, documentation, and sheer patient volume, not to mention communication across disciplines and practices. I wish I had a brilliant answer about how to achieve this balance but that is what is truly difficult.

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