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Cover Page Footnote

I'd like to express my love and gratitude to my husband, Dr. Jerry Sullivan; my deepest appreciation to my amazing team of physicians, Drs. Cheryl Nocon, Eric Moore, Nancy Mantich, and Bruce Brockstein; and my thanks to Heidi Semann and the Parotid Patient Project.

The journey from provider to patient: Lessons learned

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Abstract

The lens through which one experiences a health crisis is influenced by their personal beliefs and experiences as well as by their professional training and circumstances. Parotid (salivary) gland tumors are rare. Having more than one parotid tumor is rarer still. My experience as a clinician and researcher who was diagnosed with two parotid gland tumors was influenced by my life experiences and my professional background. This affected my reaction to the situation and the questions I asked. It also affected my expectations of my providers. This is a reflection on my six-plus-year journey and the lessons learned, both personally and professionally. The journey will be a lifelong one, hopefully full of promise and health.

Keywords

Patient experience, cancer, parotid.

In 2016, I was at the top of my game. I was a physical therapist, a clinician scientist, and a professor and Assistant Department Chair in the medical school of a top tier research-intensive university. I balanced my professional time between teaching and research. My children were launched, and my husband and I had begun to do more international travel.

First Tumor

The small lump that appeared behind my right ear didn't really bother me, but instinctively I knew it shouldn't be there. My dentist said he thought it was a "salivary gland stone" and didn't seem concerned. I showed it to my gynecologist at a routine appointment. She was similarly unconcerned but acknowledged that it wasn't really her area. As I was prepping for minor foot surgery, I showed it to my primary care physician, and she recommended imaging. Within a week, the lump had been termed a mass (a somewhat more ominous term) and I was scheduled to see a head and neck surgeon. The surgeon's office was in the cancer center – cancer was another ominous term for me.

A biopsy revealed that the mass was a pleomorphic adenoma, the most common type of benign parotid gland tumor. Parotid tumors are fairly rare, occurring in only 6/100,000 people. Surgery was scheduled 2 weeks later. My surgery was uneventful, but my recovery was bumpier than expected. The drain in my neck remained in place longer than usual because I developed a sialocele, a pocket of saliva in the wound bed. The right side of my face was weak – liquid dripped out of my mouth when I drank anything, and I had trouble closing my right eye and had to patch it at night. I couldn't feel my right ear or much of

the right side of my face. I developed "first bite syndrome," a sharp pain in my jaw when I began eating. It helped only a little bit to think about the many patients I had treated who bore their often-significant limitations with grace. I resolved to use the experience to become a more compassionate person and provider.

My surgeon reassured me that a) my tumor was benign, and my long-term prognosis was excellent, b) she'd removed the entire tumor, without breaching the outer capsule, important for preventing spillage of tumor cells and recurrence, and c) she fully anticipated my symptoms would eventually resolve. Her willingness to listen to my concerns and patiently explain her thinking were essential to my recovery. Although I tried to be optimistic, as a healthcare provider, it was easy for me to focus on the patients I'd seen with adverse outcomes. I pored over the medical literature for any information on parotid tumors.

For me, being a clinician was a mixed blessing. It equipped me with some medical knowledge, just not the right medical knowledge. However, it emboldened me to ask multiple questions and to advocate for myself. My husband is also a clinician, although like me, head and neck tumors are not in his wheelhouse. We came to each appointment with a written list of questions and took notes during each exam. I sometimes wondered, if knowing our backgrounds, my providers took a very deep breath before coming into the exam room with us. However, we were pleased and privileged that my team engaged us as key partners in every decision to be made.

Fortunately, my surgeon was right. Within 4-6 months I was back to baseline, having resumed all of the things I had previously enjoyed. My scar was minimal; my hair

mostly covered it. I resolved to allow the experience to make me more patient and understanding; only my family, colleagues, students, and patients can attest to whether that actually occurred. I was very grateful and can honestly say that I gave my tumor almost no thought for five pleasant and productive years.

Second Tumor

Gradually, however, I began to notice new symptoms in my jaw. I experienced a dull pain, primarily when I was eating. I had been told that recurrence rates were low and preferred to think that I was just having TMJ pain that it was nothing to be concerned about. However, I read that every sixth patient has multiple parotid tumors, but those are more likely to be synchronous, rather than years apart.¹ After a few episodes, I casually mentioned the symptoms to my husband, who immediately wanted me to seek care. However, it took multiple occurrences, including episodes of trismus, difficulty opening my mouth, to convince me to finally contact my physician.

My prior surgeon had left the area and I was referred to new physician. This interaction was drastically different from the one with my first surgeon. The vast majority of the visit was spent with a resident. The surgeon actually spent less than five minutes with me. He palpated my jaw for a few seconds and said that tumors like mine don't really return, but if they do, they don't cause pain. I reiterated that pain was one of my chief symptoms and he said I could take Ibuprofen. I felt that this surgeon minimized my symptoms, my concerns, and medical history. He grudgingly agreed to order a CT scan. Two days later, the scan revealed another parotid gland mass. To date, this surgeon has never contacted me to discuss the CT findings or a plan.

I cried. I felt abandoned and unsure about my next steps. I spent several days reaching out to every medical person I knew, asking for referrals and opinions. I located a [website](#) founded by someone who had experienced a parotid tumor. The site is designed to provide information and support to people like me. It included a series of videos developed by the patient with her surgeon. As I pored over the videos, I began to feel calmer, better educated, and convinced that I wanted to be seen by this surgeon; however, he was located five hours away from my home. My husband and I decided it was worth the trip.

We found this surgeon was compassionate, patient, and thorough. He listened carefully to all our concerns and answered our numerous questions. He was balanced yet patient-centered in explaining his thinking. We had a lengthy conversation about the pros and cons of a second surgery, which due to the accumulated scar tissue, was riskier than the first one. The surgeon ended the consultation by assuring us that whatever decision we

made, he would “do his very best for me.” Those words helped ease the anxiety as we made the decision to schedule the procedure. I underwent surgery in May 2022. Afterwards, my surgeon seemed almost as pleased as I was at how successful the procedure had been.

As with the first surgery, there were some bumps on the road to recovery. I had moderate weakness in my right lower face which interfered with eating and talking. On the ironic bright side, my recovery occurred during the COVID-19 pandemic. Mask-wearing actually prevented outsiders from noticing my lopsided lower face and made me somewhat less self-conscious. I also experienced considerable wound swelling. The pathologist had some questions about the final diagnosis of my tumor, so additional analysis was recommended. It took several weeks to get the results.

My surgeon patiently responded to my numerous concerns about my facial weakness, wound swelling, and uncertainty about the pathology. Our interactions were via telehealth, and I was pleased by the effectiveness and efficiency of the communication. I rarely had to wait more than a few hours for a response to a question. We used both text and phone calls. I sent photos of my surgical wound to show the swelling.

Unfortunately, my tumor was ultimately determined to be a mucoepidermoid carcinoma, a cancerous tumor. My surgeon seemed to understand my disappointment with a cancer diagnosis but assured me that since my tumor was low-grade and had been completely resected, I had a very good prognosis.² When I asked him to help me understand why I had experienced two different tumor types in the same gland, he said there was likely no explanation; it was simply a case of lightning striking twice in the same place.

As a physical therapist, I consider myself an expert in muscle reeducation, including facial muscles. I reviewed what was known about facial nerve rehabilitation³⁻⁶ and was diligent about my self-prescribed routine of stretching and strengthening exercises. A month after my surgery, I read about a clinical trial that reported promising results using a new intervention for facial weakness.⁷ I contacted the author and got access to the patient and provider versions of the app the researchers had studied, and I used it religiously.

As my wound became less tender, I incorporated scar massage. One of my own areas of research has been in the development of patient reported outcomes⁸; therefore, I was very interested in trying to objectively track my own progress. I located two scales to assess outcomes in individuals with facial weakness. I charted my progress with the Facial Clinimetric Evaluation Scale and Synkinesis Assessment Questionnaire.^{9, 10} It has been important for me to be able to interpret my condition through a lens that

I find both familiar and useful, and to leverage my professional skills to enhance my recovery.

Patient Feedback

One of the things that helped me through difficult times is sharing feedback with my providers. When I am training novice clinicians, I stress that seeking and reflecting on patient feedback can help one to become a better provider.^{11, 12} I wrote two letters: one to the medical director at the hospital where I had my successful second surgery, and one to the medical director at the cancer center where I felt my treatment had been less optimal. I copied both surgeons on the respective letters.

Typically, I don't receive any response to the letters I write to providers. However, I received a response to both letters. The Department of Head and Neck Surgery at the hospital where my tumor was resected wrote to thank me for the feedback. The medical director at the cancer center asked if we could talk. He asked for the details of my experience and listened patiently to my concerns. He assured me that his goal was that each patient receives high quality, compassionate care and that he would use my feedback to help achieve that goal. I felt good that my input had been well-received and hoped that it might make a positive difference for the next patient.

Today I am one year tumor-free. Every six months I see my oncologist, my oncologic dentist, and have imaging done. I am in regular contact with my surgeon via telehealth. Although the electronic medical record is viewable to all, I am the captain of my team and take responsibility to make sure that each knows what has transpired with the other providers. I continue to read literature about my condition and bring questions to my caregivers. For example, my oncologist and I recently reviewed guidelines for surveillance of parotid malignancies and discussed how they should influence my plan of care.⁶

Going forward, I realize I need to reconcile my left and right brain, to achieve a brain balance and a healthy attitude about life. Sometimes this is challenging. For example, my left brain has read the statistics and understands that my prognosis is good. The cancer-specific survival rate for those with my tumor type and grade is extremely high.² I was treated by a surgeon with great expertise who completely resected my tumor. Yet, my right brain says, yes, but there is virtually no data for those with the two different types of tumors I experienced. If, as my surgeon said, I am a victim of lightning striking twice in the same area, might I also defy the statistics about cancer-free survival?

Another right-left brain issue that I sometimes struggle with is related to ongoing mild symptoms. My left brain

says that these occasional twinges and feelings like little electric shocks are simply a product of the tissue remodeling that occurs with healing. My right brain says OK, but these feel very similar to the symptoms I experienced just before my second tumor was diagnosed. Does that mean there will be another tumor? Each time I have a negative scan or exam, my left brain cheers, and that helps quiet my right brain. Short of a daily CT scan, there will never be a way of knowing minute-by-minute what is going on inside my head, and I know I need to make peace with that.

Lessons Learned

I would like to conclude with lessons I learned during this journey.

Lesson 1

For the patient: Find a provider who understands what you know and (perhaps more importantly) don't know and can speak in a language that is clear to you. One constant in the excellent care I received was the willingness of my medical team to listen patiently to my questions and take the time necessary to make sure that I understood the pros and cons of the various options I had in making important health decisions.

Lesson 2

For the patient and provider: Allow dialogue about not just the medical condition, but the patient's response to the situation. My providers have given me permission to express my fear, confusion, frustration, and uncertainty. I believe that knowing what is in my head and heart helps my providers take a more holistic view of my care. As a patient, I have greater trust in a provider who has that lens.

Lesson 3

For the patient: Take support when it is offered and ask for it when you need it. As a provider, I am very accustomed to providing support; accepting it is another thing. But navigating a health crisis requires a team. I had remarkable support from my husband, other family members, and friends. Without that, this would have been a much more difficult journey.

Lesson 4

For the patient and provider: Don't ignore new symptoms. We all know our bodies and what is normal and not normal for us. Similarly, I don't believe we should allow providers to ignore our symptoms. Patients have the right to have their symptoms heard and understood. Providers shouldn't seek to make a patient's symptoms fit a pre-conceived understanding of a condition. When that happens, it's time to find another provider.

Lesson 5

For the patient: Leverage your strengths to help with your challenges. I found it very useful at times to take off my patient hat and put on my professional hat. It provided a welcome distraction from the emotion of the situation. It changed my focus from having things done TO ME to being IN CHARGE of mastering information. It's important to recognize each and every person brings a wealth of experiences and talents that might be channeled towards recovery.

Conclusion

People like me become healthcare providers because we want to help others optimize their health and care for those who are experiencing health challenges. We rarely consider how we might respond if faced with a health crisis ourselves. The skills we acquired during our professional training can help us navigate our own health challenges. We can also take the opportunity to leverage our experience as patients to make us more compassionate caregivers.

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