

SUNIL J. PATEL, M.D.: So the pineal gland is in almost the center of the brain. I mean in brief, I would say that most people don't know what the function of the pineal gland is in humans, almost like the appendix in the belly. We don't know what the appendix really does or its purpose in human GI track. In the same way, the pineal gland we really don't know what its true functions are. We do know that it produces melatonin, but whether that melatonin production contributes to sleep wake cycles or what, we don't know.

We also know from neurological experience that if you remove the pineal gland for whatever reason, because it's got a cancer or something, that there is no objectively measurable functional differences or changes in the humans related to the pineal glands. So neurosurgeon's view of the pineal is that, OK, that's the pineal gland. It's a very tiny gland. It's about the size of the tip of your finger in an adult human. And sometimes it forms cysts, but cysts are benign collections of fluid in about any gland in the body.

And so sometimes these pineal glands will look a little cystic and so on. There's a little cyst but there's nothing to do for it. It's not related to your symptoms or whatever. So many times patients who come in with a radiological report of a pineal gland cyst, the nurse is going to say, well that's just the pineal gland. It's nothing.

I had a lady in my clinic who was referred to me with quote, "a pineal gland cyst." she was in her 20s early 30s, I can't remember her exact age. And she had a lot of symptoms I couldn't explain, things like visual disturbances, headaches, and there were quite debilitating symptoms. She seemed like a very functional individual. Socially seemed OK to me. There were no other major medical or psychological issues. She had seen a lot of different doctors and the symptoms had affected her to the point where she had to quit work, and she was mostly housebound. Couldn't take care of her kids, things like that.

Her scan showed a fairly large pineal gland cyst. And there's been no way to date there had been no literature to show that the size of the gland cyst, or the size of the cyst correlates with symptoms. And so this was going to end up being for me another patient that I would say, oh you just got to pineal cysts. Yeah it's a little large, but I don't think it's related to your symptoms. And I couldn't do that. I stop short of telling her that. I thought to myself that she's debilitated from all this. There is nothing else going on in her brain. She has no other metabolic disorder, she has no other medical issue going on. She seemed to be a normal

individual.

Then maybe the cyst is giving her symptoms. And so I removed the cyst and two things surprised me about that patient when I removed the cyst. One was a post-operative visit within two weeks, she came to me and the stitches removed, and so I met a different person. She-- 80% of her symptoms had resolved and she'd been suffering for six, seven years. I can't recall exactly.

And the second shock for me was the report I got from the pathologist who reported that this was a pineal cytomas and not a pineal gland cyst. Now, pineal cytomas are benign tumors of the pineal gland. They are not cancerous. In fact, most of them you remove them because of their size, but there are smaller ones that you just leave alone. And so what talked me out of that one case is that I need to be careful about all these patients being referred to me that are quote, "patients with pineal gland cysts," that it may turn out that they're not all benign cysts, that some of them are benign tumors.

And so they need to be followed. They don't need to be discharged. That go away, you're crazy, or something like that. And perhaps more importantly that removing these might relieve these patient's symptoms.

There is probably about five or 10 neurosurgeons around the world who, like me, have had some increase experiencing-- experience with listening to these patients and recording their symptoms. And we're about to publish a paper too, and we're not the first. But where we've put together this collection of symptoms that point to the possibility that this is a symptomatic pineal cyst.

You know, headaches obviously are important factor. But there are some cognitive things that these patients have and it's varied from patient to patient. They have these unexplained episodes of confusion, or episodes of speech difficulty. They've had some visual symptoms that are episodic. They even have double vision. Their pain is anywhere from a global headache to sometimes very specific. They say I have pain, pressure behind my eyes. A lot of these patients talk about having insomnia.

And you as I mentioned earlier, we don't know what the pineal gland does. It produces melatonin and so is this the pineal-- the pathological lesion producing abnormal melatonin and causing them to have insomnia? They have some other cognitive issues like short term memory issues. I had already mentioned confusion. These are some of them. And then there

are these rare patients have come in with these odd and unexplained episodes where they're either numb in their arms or legs, they have some balance issues, et cetera.

That correlated with what I see on the MRI raises my level of suspicion. So these days when I have patients just send me a note saying, look I have these symptoms and I was told I have a pineal cyst. I want to look at the MRI because there are some things that I've sort of sensed on the MRI that looks a little different and more suspicious of this being cystic tumor the pineal gland.

The first patient was about four or five years ago and the first two years or so it would be the occasional patient that I would get as a routine referral to me. I'm a neurosurgeon here at home MUSC who sees a lot of patients with intracranial masses. It's my sub-specialty area. But over the past three years I now see anywhere from two to three patients a week that come from all over the country, that have found my name as one of the neurosurgeons in the country that treats these lesions, that evaluates these lesions. And I've operated on over 30 patients now with these lesions.

Some of these patients that I see just have a pineal cysts. They don't have symptoms and I don't do anything with those. I do tell them that you do have a cyst and there is a small possibility it's a benign tumor. So don't stop following-- getting this followed at least every year or two get a scan. Or earlier if they have symptoms.

If these patients are well-selected and their symptom complex seems to fit and their MRI is highly suspicious and we remove them, then 90% plus of these patients have complete resolution of all their symptoms. And there are a few patients that have other things going on that may not improve.

For example, some patients have a long history of migraines. And so they are migraineurs, but on top of that they had also symptoms from the cyst. So you remove the cyst and some of the other symptoms go away, but not all their headaches go away. So those are the few percent of patients that have other things going on. But 90% plus of patients get better after you remove it.

Any surgery has risks, right? There is no surgery that I know of that does not have risks. But the general risks are you are operating inside the brain. And we use very minimally invasive techniques to do surgery these days. The use of a microscope or an endoscope, small

incisions. We have much better systems in the operating room to help guide the pathway for the surgery. But the general risks are things like infection or bleeding.

What I have experienced with these pineal patients is that while 90% of them don't have any complications, a small percent will have either some lingering double vision for a couple of months. Some of them will have pain at the site of the surgery where we go in. These are not debilitating symptoms. We've not had any catastrophic complications. Although when you operate in the brain you can. You know, there's always a risk of a hemorrhage or a life threatening infection or something like that. But we've fortunately not experienced the bad complications

I think the message is this, these days about every specialty-- primary care and sometimes specialists-- order MRIs of the brain for whatever symptom a patient has. And neurosurgeons included will get a report back that the patient has a pineal cyst, that unlike the recent past, we shouldn't ignore that diagnosis. We ignored it before because we thought, oh that's just a gland with a little cyst. The gland that we don't know what it does. But if a patient has a pineal cyst, that if the patient's symptoms are not easily explained by anything else going on, that not to discard that radiology report of a pineal cysts. And refer to a specialist neurosurgeon who at least routinely evaluates these patients with pineal gland cysts. Just to be sure that the cyst is not the cause of symptoms.

So the take away message is not all pineal gland cysts are asymptomatic, and not all of them are non tumorous, or non-neoplastic meaning. The majority of the symptomatic ones have turned out to be benign tumors, and removing them does provide relief from symptoms.