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WHAT YOUR PATIENT IS THINKING

What I never consented to

Andrés J Lessing describes the worry of incidental findings and how the process of giving consent could be improved

Andrés J Lessing

I have a complex medical history and have experienced many tests, procedures, and surgeries. Over the years, I have consented to seemingly endless risks that came with these procedures, including adverse reactions, infection, bleeding, nerve damage, function loss, and even death. But one element was never included in consent forms or conversations—the possibility of an incidental finding. I have never consented to what I now know is common and called “incidentaloma.”

I am 41 and have neurofibromatosis type 1 (NF). I have survived NF related cancers three times and participated in multiple investigational studies along the way. These included myriad magnetic resonance imaging (MRI) and computed tomography (CT) scans and surgeries. Some of the scans showed lesions that were unexpected, and these prompted further discussion with my neurologists, surgeons, and physicians, as well as additional treatments, and extra anxiety on my part.

I cannot recall once the possibility of incidental findings on the consent forms I signed, or—more importantly—in discussions with my doctors.

The worry of incidentalomas

One of my first incidentalomas was found after surgery for an NF related malignant peripheral nerve sheath tumour. I woke up without sensation from the top of my right shoulder down through my hand and fingers. An exploratory MRI scan detected a growth near the pineal gland in my brain. Questions were raised about metastasis, new malignancy, and more, even though none of this explained the sensory loss. Every six months thereafter, lying as still as possible in the loud MRI scanner, I wondered and worried about the growth in my brain. After years of biannual scans, I located a childhood MRI scan that confirmed the growth had been there all along and was likely a benign pineal cyst. Thus began my journey with incidentalomas.

Ten years after my last recurrence of the cancer was removed, I volunteered for a full-body MRI scan as part of a study. The scan identified a lesion in my right axilla near the site of my many surgeries and radiation field. My doctors ordered a follow-up MRI three months later, which showed growth of the lesion and led to a fifth surgery in this area. The lesion turned out to be skeletal muscle with atrophy, fibroadipose tissue, and fat necrosis and very fortunately was not a cancer recurrence. However, CT scans I'd had in preparation for the surgery found thyroid nodules not previously seen. Additional

investigations ensued, as did doctors' visits, further studies, and continued worry. The nodules turned out to be common and nothing of concern. With each benign finding, I was initially shocked and overwhelmed with gratitude. I thanked my team of doctors and thought of friends who did not survive my rare type of cancer. But each incidentaloma resulted in more tests, more loss of function, added worry, and hardship.

Reframing the consent process

Some will say it is not possible to address every potential outcome in consent. However, a simple reminder of the possibility (indeed, high likelihood) of incidental findings—and what we might do to address them—would have been helpful. My choices might have been the same, but I believe we would have felt better prepared for whatever was to come. The consent process should educate patients on the benefits and risks of treatment and should include discussing the possibility of incidental findings and possible responses, including watchful waiting rather than further tests and more surgeries. I share my story because I wish my doctors had discussed with me these possibilities during the consent process.

What you need to know

- Discuss with patients the potential for incidental findings
- Incidental findings can be stressful for patients, who are likely already very anxious
- Ask pre-emptively (during the pre-treatment consent process) how a patient might wish to deal with incidentalomas. Accept that patients may opt out of acting on incidental findings. Explain that simple acknowledgment and/or watchful waiting is often a reasonable strategy
- Discuss with patients all incidental findings that appear in their radiology reports

Education in practice

- How could you discuss with a patient the potential for incidental findings?
- When might you ask a patient about how they would like to deal with any incidental findings?
- How could you record and share the patient's wishes about incidental findings?

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