

The Insurance Intelligencer

5/25/11

“Experimental for this particular patient”

What if your insurance company denied a lifesaving treatment because it was “experimental” for you, just you, and nobody else but you?

In the case of Patricia from New Jersey, that is exactly what happened.

The denial

Two weeks ago, I heard from Abbie in New Jersey. Her mother Patricia had been diagnosed with appendix cancer, and she needed the same treatment that I had six years ago—cytoreductive surgery and heated intraperitoneal chemotherapy (HIPEC). Horizon BC/BS had denied the surgery as experimental. Not experimental in general, and not experimental for appendix cancer. Experimental just for this one patient.

Patricia has a sub-type of appendix cancer that is so rare that my expert surgeon has only seen twenty cases of it—out of two thousand surgeries: adenocarcinoid with goblet cell or signet cell morphology.

The denial says ...

- a) This treatment has no proven benefit for the particular diagnosis or treatment of a patient's particular condition.
- b) Not generally recognized by the medical community as safe or effective for the patient's particular diagnosis or treatment of the patient's particular condition.

I could hear the insurance company saying, “This patient has a really rare cell type. Let’s call the treatment experimental for that particular cell type. She will never figure it out. There are so few patients with this cell type—she will never find any studies or proof about that type in particular. Easy denial, slam dunk!”

Not that easy. I was about to immerse myself in the murky swamp of appendix cancer pathologies and terminology ...

Is it appendix cancer?

Horizon BC/BS’s medical policy statement for cytoreductive surgery and HIPEC says: This treatment is medically necessary for pseudomyxoma peritonei. It is experimental for all other conditions.”

In this denial, Horizon BC/BS exploits the great confusion surrounding the terminology used to describe appendix cancer. Even the experts don’t agree on what the words mean.

Some use the term “pseudomyxoma peritonei” as an umbrella term, to cover all types of appendix cancer. Some use the term just to refer to the less aggressive forms of appendix cancer. And some use it just to refer to the mucin which is produced in great quantities in the less aggressive forms of appendix cancer.

How did I prove it?

Insurers don't care if we need a treatment. They do not care if our doctors believe that we need a treatment. They don't care if it is a tried and proven treatment, or if it is the only treatment that will save our lives.

There is only one question that insurers care about, when deciding whether or not to pay for a treatment: “Are we required to pay for this, under the terms of your contract?” We must prove—in a half-dozen ways—that they will be required to pay.

How did I prove it in this case?

- This particular cell type—adenocarcinoid with goblet cells—is a sub-type of the group of mucinous appendiceal cancers called “pseudomyxoma peritonei.” The two leading experts on appendix cancer pathology—Dr. Ronnett at Johns Hopkins and Dr. Paul Sugarbaker—agree on this.
- Horizon's medical policy #00035 specifically approves this treatment for pseudomyxoma peritonei.
- Horizon's medical policy #0035 does not mention this patient's cell type. This medical policy does not expressly state that “this treatment is experimental for adenocarcinoid with goblet and signet cells.” It does not mention her cell type at all.
- Horizon BC/BS has paid for this treatment for a patient with goblet cells and signet cells before. I gave her name, name of surgeon, and date of surgery.
- Horizon BC/BS has approved this treatment seven times—for all different cell types included under the umbrella term “pseudomyxoma peritonei”—including this patient's particular cell type. I give names and dates for the seven Horizon cases.
- All major insurers routinely approve this treatment for this particular cell type. I list eleven cases of adenocarcinoid with goblet cells from my precedent list.
- All major insurers pay for all different types of appendix cancer. I always include my entire precedent list of 115 cases where insurers have paid—with names, dates, and diagnoses.
- In their denial letter, Horizon invents a whole new definition of “experimental” (“for this particular patient”). I point out to Horizon that—when there is a contract in place, you don't get to change it.

- The reviewer on the denial letter was a family practice physician. He was not qualified to render an opinion on the treatment which was at issue.
- The in-network doctors know nothing about this disease, and do not know how to treat it. I prove this by telling the Bad Medical Story.

It took me thirty-eight pages to prove this case with facts. I faxed and emailed the appeal on Sunday night. Horizon BC/BS reversed their denial by Tuesday morning.

I have to get up earlier and earlier in the morning—in order to outsmart these insurance companies. I can do it, but how many others can do it?

How many patients who are suddenly diagnosed with appendix cancer—and whose surgery is denied—would ever be able to sort out the fine points of pathology, and be able to argue them in an insurance appeal?



Mom Patricia is on the left, daughter Abbie in black.

It is time for insurance companies to be held accountable for their decisions. There is a bill which has been written in California which will do just that. This bill could change the balance of power between patients, doctors, and the huge monopolies which are modern-day insurance companies. About this bill, more will soon be revealed ...

Peaceful and happy Insurance Warrior-ing,

Laurie Todd

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