Unnecessary uncertainty is unacceptable

The old commitment to giving special care to physician colleagues as mentioned in the Hippocratic Oath, is no longer operative and in fact should not be. All citizens should be treated equally, but they should also be treated promptly. Too often they are not. My story is a case in point. I've had lots of experience being a patient for impaired kidneys, gout, hypertension, glaucoma, scleritis, multiple basal cell cancers, lymphoma, breast cancer — and the most recent arrival — thyroid cancer.

In March 2011, my general practitioner (GP) wanted a post-thyroidectomy consult and referred me to an oncologist. Six months later, in early September, I saw him, a kind and skilled clinician. Palpating my neck he announced to my amazement that I had bilateral lymphadenopathy and that lymphoma or thyroid metastases must be ruled out. Why amazed? Neither I nor my GP could feel anything. Ultrasound was scheduled. Was it naive to expect that ruling out metastatic disease would proceed promptly? It was very naive.

The ultrasound was scheduled for Dec. 19: three and a half months of uncertainty. After the exam, the concerned technician wanted confirmation that I would be seeing my oncologist that very day. In fact, my appointment was for mid-January. Only then were needle biopsies ordered — to be done so I was told, within two weeks. They weren't. It would be three weeks and then only because I gently reminded the appropriate people.

Biopsy day finally arrived. Lying on the table, submitting again to ultrasound, I was suddenly informed the procedure was cancelled. Why? My appointment was for 3 pm. I entered the procedure room at 3:40 pm. The pathologists go off duty at 3:30 pm. That's why. But why do you need a pathologist? In order to confirm that an adequate tissue sample had been harvested. If inadequate, you proceed elsewhere for a core biopsy. On my return visit the following week, the staff radiologist was swift and smooth.



I was told the pathology results would be available in one week. With no word after two weeks, I inquired and learned that the report was "no metastatic disease." Three cheers! But, that is not the end of the story.

Early in March, I saw the oncologist who follows my breast cancer. The first words spoken to me in the examining room were: "Dr. Baines, we are very concerned about your neck!" I was puzzled. It turns out that the pathology report makes very clear that the biopsy site from which the tissue came is not the site of the nodes identified as suspicious on the ultrasound. So here we go again: more uncertainty. An ultrasound was scheduled for the very next morning and a return visit to the oncologist the next week. Promptness appreciated. Another biopsy has yet to be scheduled.

I draw three generalizations from this:

- Physicians cannot unquestioningly assume that their colleagues have done what they were expected to have done. The biopsy came from a level 5 node when it was supposed to be a level 2 node. Repeating the biopsies means the health care system will have to pay twice.
- Prolonged waiting times affect too many people.
- We should re-examine how our medical system is doing. A very wise British surgeon, Michael Baum recently said: "Screening leads to an

epidemic of breast cancer, but survival keeps improving. Thus we need more screening, leading to more disease and better survival until everyone has cancer and the survival after screen detection is the same as the general population. Hurrah! Shame there's nothing left to spend on sick people" (Michael Baum: personal communication. 2012).

His observation applies to more than the consequences of breast cancer screening. There probably is too much searching for disease in the worried well. An Oakville GP told me that she cannot order the most routine of x-rays without the report concluding: "should consider CT scans and MRI." Are too many of our facilities choked up with the worried well, and too many of the truly unwell subjected to unnecessary and unacceptable delays? The costs must be considerable.

In my case, even after seven months, diagnostic uncertainty continues. The diagnosis could have been finalized at best in one week and at most one month. Uncertainty is hard on patients and maybe more so for families. With life already full of uncertainty, unnecessary uncertainty is unacceptable.

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