

When impatience is a virtue

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There can be few paradoxes quite like the life and death of the former mayor of Toronto, Rob Ford. As a cancer patient, I watched how a man so publically vilified for his “personal life” showed all of us the realities of cancer and its treatment in 2016. Here, I try to express how my own experiences with cancer have certainly shown that the “war on cancer” is far from over.

I have played many roles in my life: wife, mother, physician, coroner. In each of those roles, I have followed the traditional adage that “patience is a virtue,” and expected that by being “patient,” most of life’s misadventures and challenges would resolve or be worked out. So what has led to this change in my attitude and a frank refusal to be quiet? Well, when you transform from a health care provider to a cancer patient with a life-threatening disease, impatience becomes a virtue! You come to learn that things have to change and that they had to change yesterday!

After being told that I had a lymph node–positive breast cancer, I was thrown onto the emotional rollercoaster of a cancer diagnosis. I realized that we cancer patients must think and act like warriors in our battle with cancer and start asking questions about the manner in which clinical services, the health system, and cancer research are organized. As I went through repeated doctor visits, breast surgery, chemotherapy, radiotherapy, ovarian removal, endocrine therapy, and physiotherapy, it became increasingly clear to me that, although my treatment was following the pathway of “evidence-based medicine” and “best-practice clinical guidelines,” the evidence base was, in reality, “sparse” for many areas of my own personal care—a realization that was even more surprising given the global prevalence of cancer.

Here, I have broadly divided my thoughts and questions into prevention of cancer, treatment of cancer, urban myths, and finally, the future of clinical research. I am not trying to point fingers at individuals and organizations, but I do feel that my skill set as a physician and coroner—and now as a patient—allows me to pose questions and to learn from some of the great advances experienced in other fields of medicine.

Prevention of Cancer

As a family doctor, appropriate care for blood pressure, cholesterol, and diabetes in my patients has resulted in significant reductions in both heart disease and stroke. By screening for colorectal, prostate, and cervical cancer, we are hopefully enabling diagnoses at an earlier stage. But with respect to cancer prevention, we family doctors need greater education on how to effectively integrate alternative lifestyle strategies (for example, diet, weight control, and

exercise) and chemoprevention (for example, tamoxifen) into broad clinical practice. We also need more advice on areas of patient care that appear controversial and confusing to physicians and patients alike. For example, what is the true benefit of screening mammography and breast self-examination? There is so much controversy that it is straining the relationship between patients and their family doctors and oncology specialists.

Treatment of Cancer and Navigating the Cancer Care System

As I plunged into treatment, I became very aware of questions around the “process” of cancer treatment delivery within the health care system. For physicians involved in cancer care, the processes seem routine. Yet, as a patient, many seem bizarre.

Why is patient care a lottery, not only in terms of the cancer centre to which a patient is referred, but also in terms of the physician or physicians seen within that centre? As more health care workers become involved in an individual’s care, the greater the challenge of providing consistent and understandable messages to the patient. Even though patients know (or assume) that their doctors are communicating with each other about their case, there can still be differences of opinion about the best treatment plan. In the waiting room, some patients did not understand why they needed certain procedures, and others (like me) had questions about why they had cancer in the first place.

Another frustrating aspect of cancer care is the incessant need to keep writing out one’s past medical history with each test or each meeting with a new health professional. It creates much anxiety, doubt, and insecurity in the health care system at a time when patients are putting their entire lives into its hands. Why, in the era of Internet, are appointments still being sent by regular mail? More importantly, why, when the appointment paper says that a visit will be with our designated oncology specialists, might we instead see a clinical fellow or nurse practitioner instead? My hope would be that by seeing “replacement” health care providers, imaging results might at least be provided earlier. Such coordination does not occur, meaning that you wait even longer to see the “primary” oncologist—the one you assume is driving the bus.

With respect to the treatment of my cancer, I can draw on my own experience to realize that the popular mantra of “personalized medicine”—providing the right treatment to the right patient at the right time—is not quite here for those of us living in the real world. The reality is probably closer to the term “reasonable care,” meaning care based

on clinical trial results evaluating all types of breast cancer patients. Why are there no large clinical trials evaluating the role of chemotherapy for my particular type of breast cancer, lobular breast cancer? Why, when the lobular type accounts for 15% of all breast cancers (>2000 new patients annually in Canada), is there so little lobular-specific data out there? Why are we still so unsure about the relative and synergistic benefits of radiotherapy, chemotherapy, surgery, and endocrine therapy in my management? What is the real benefit of future mammograms in my care? What is the role of magnetic resonance imaging? Will either one actually improve my chance of survival?

When my husband and I were first presented with the surgical pathology results, we were told that it was “good news.” Although having metastatic breast cancer hardly seemed to be “good news,” we soon came to realize that “strongly hormone-positive” meant that long-term treatment options were available. But what about diet and vitamins? Do the risks of the anticancer treatments—such as secondary cancers, chronic lymphedema, and other organ damage—outweigh the benefits?

Although I have gone through the active treatment “experience,” I still have no shortage of questions about the roles of various investigations and treatments. For example, plenty of high-quality evidence shows that I did not need a radiologic evaluation for overt metastases because the risks significantly outweighed any benefit. However, how does that knowledge help me as a patient? Does avoiding the anxiety, cost, and potential long-term harms of the scans outweigh the knowing that my scans were normal? Why did my medical and surgical oncology team avoid unnecessary extra imaging, while at the same time I had two necessary planning imaging sessions with radiotherapy that were not to be used for diagnostic purposes?

Urban Myths

As a family doctor, I thought that I was well-versed in health-related urban myths: those areas of care that continue to be perpetuated by the Internet, friends, cancer “survivors,” and some well-meaning health care providers when there is either no evidence to support them or, more commonly, there is plenty of evidence to show that they are nonsense.

We need better strategies to address urban mythology. Quite simply, the guilt of “catching cancer” is so great as to inspire belief in the myths. They become all-consuming and concerning to patients: “Too much soy.” “Harmful effects of deodorant.” “Avoid perfumed hand sterilizers.” Should we not be drinking tap water? Is green tea good or bad? Should I never eat red meat?

I first laughed when I saw one Web site state that “lack of sex leads to breast cancer!” Then I was saddened that other vulnerable women were bombarded by the same questions and were perhaps taking that statement at face value. I can only surmise that the Web site was interpreting the fact that woman who do not bear children or who delay parenthood are more at risk. How is that information really helpful? Another prevalent myth is that after lymph node surgery, we are told not to have anyone draw blood or take blood pressure from the affected arm. Upon further investigation, studies have shown that there is no validity

to avoiding taking blood or blood pressure on the affected side; in fact, upper body exercises promote better healing.

I was told by the radiation technicians and nurses to avoid swimming during radiation, and yet the doctor told me that other patients had swum every day during radiation and in fact had perfect skin. Swimming for me is a great therapy for my axilla seroma and a lot less expensive and painful than multiple drainages and massages; however, I had to find that out on my own. I had no mouth sores because I believe that eating green apples alleviates yeast. Again, I found that out experimentally.

There are Web sites and foundations with a lot of interest in cancer, but why then are the answers so slow to come and the changes to happen? I am also increasingly aware that many of the myths are repeated to various health care workers at various times, wasting everyone’s time. Frustratingly, much of the advice about nutrition, vitamins, control of hot flashes, management of depression, and exercise was not evidence-based, but anecdotal. Where is the proof that changing habits is actually going to prolong life!

Clinical Trials

Why is clinical trial accrual falling in Canada? I am aware of many initiatives to improve accrual that are underway, but still, fewer than 5% of all cancer patients are enrolled in trials.

It is evident that there is a long way to go in improving the treatment of cancer. Indeed, many of the questions and suggestions mentioned here will require appropriately designed clinical trials. Should we as patients be demanding that our health care workers talk to us about trials? A simple mandate has to be “a trial for every patient and a patient for every trial.” While appreciating that there are institutional, regulatory, and patient- and physician-related barriers to performing clinical trials, it is time to mandate that every patient be informed about all eligible trials. If patients are interested in a trial, then seamless processes should be put in place for the patient to participate. We know that involvement in clinical trials will improve care for all.

DISCUSSION

I believe that my own cancer experiences make me a better mother as I try to “not sweat the small stuff,” and I truly do savour each day. I play Christmas music every day!

I am hoping that my experience has made me a better physician. I am sensitive to the costs of cancer care (time off work, wigs, hospital parking, physiotherapy, massage therapy), and I therefore don’t make assumptions about accessibility. I have embraced the “Choosing Wisely” campaign.

I have been asked more than once by cancer patients to interpret the meetings they have had with their cancer doctors. I am increasingly aware that those meetings are often overwhelming and heightened experiences.

I know that any news, even bad news, is better than waiting and wondering. My geriatric patients and our grandparents always whispered when they talked about cancer. Why are we still whispering? I have been very open with my patients about my cancer. I hope that, by making them aware, I am helping them to prevent or detect cancer

at an earlier stage. I want patients to have assurance that the advice they are given is sound and evidence-based, and I want everyone to stop whispering!

SUMMARY

So, to go back to the beginning of my rant: Is impatience a virtue? If you had asked me a year ago about my impressions of cancer services and cancer research in Canada, I would have said that we are at the top of our game! Now, I am ashamed to admit that we professionals have become content with anecdotal answers to serious life-ending questions. Being faced with a life-threatening illness has made me impatient. I want action, and I want it now!

While I know that being “impatient” is an un-Canadian attribute (much like the personal life of Rob

Ford), I do believe that his death after a short battle with cancer makes us realize how “impatience” about cancer care and research really can be a “virtue.”

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