ETHICS

The gaps in care

By Philip C. Hébert, MD, PhD, Emeritus Professor, University of Toronto

I was going to write this column about the ethics topic of the year—perhaps the decade—in Canada, and that is physician-assisted death. However, there are many reports on this topic (including one from a Task Force from the Joint Centre for Bioethics that I chaired) and it seems like too gloomy a topic to write about this time of year. (I am writing just before Christmas.)

Instead, I am going to write about the gaps in care—the ethics of unintentionally hastening the death of a patient through the failure to care—where more care, not less, should have been provided. This can also be a gloomy topic. Ethics seems too often concerned with death talk. But ethics is also concerned when patients are treated ‘unfairly’—when they don’t get the care they deserve, that their condition calls for, and that other similarly situated patients would get.

I became agitated recently after listening to one of Brian Goldman’s broadcasts from his CBC show, White Coat Black Art, entitled, “Falling through the cracks”. It is the story of a 31-year-old Alberta man, Greg Price, who died in 2012 of testicular cancer. His father, very polite and understanding, tells his son’s story.

continued on page 2
The gaps in care

...continued from page 1

of missed opportunities, and a failure to care—of a patient who ‘fell through the cracks.’

In 2011, Mr. Price, a licensed pilot, had a routine recertification physical by a Department of Transport (DOT) physician. He was noted to have a ‘thickening’ of his testicular epididymis and told by the doctor to keep an eye on it. At that point, the DOT physician apparently considered the possibility of testicular cancer—he had seen, he later told Mr. Price’s father, a similar case before. It is unclear if the patient was informed then about this possible diagnosis.

Several months later, Mr. Price saw this same DOT physician for a skin rash. He noted for a second time the swelling in the epididymis and decided to refer him to a surgeon. It is still not clear what Mr. Price was told. The appointment was made for 93 days away. (This physician did not learn until much later how far away the referral was.)

While waiting for that referral, Mr. Price developed back pain that he thought was a sports injury. He went to another doctor at a walk-in clinic about five weeks after seeing the DOT physician. This doctor ordered an ultrasound and other x-rays. The abdominal ultrasound took place in just over a week later. It showed that Mr. Price had an intra-abdominal mass. The patient was informed of the potential seriousness of his condition and a CAT was recommended. But rather than ordering the CAT himself, the radiologist referred Mr. Price back to the walk-in clinic doctor. The clinic faxed a request for a CAT scan and the appointment was made for several weeks later.

A week after the CAT, the patient, who had not heard from the clinic about its results, had to phone them. He was informed that the ordering doctor was no longer working there. The doctor had apparently not arranged a follow-up for Mr. Price. Another primary care doctor, however, saw him and ordered a scrotal ultrasound. This confirmed a testicular tumour. A referral to urology was made, but this did not happen promptly.

After a week, when he had not heard about this appointment, Mr. Price himself called the urologist’s office only to find out he was away and would not be back for several weeks. He called the walk-in clinic and another urologist was consulted. Surgery finally occurred approximately 95 days after his second visit to the DOT physician. Mr. Price was discharged home, but developed pain and swelling in his legs. Unable to contact his surgeon, he went to the ER where he was reassured that he did not have a deep vein thrombosis (DVT). Sent home, he collapsed and died that night of a large DVT causing a cardiac arrest.

No one should die of testicular cancer these days. Did Mr. Price have an incurable form of cancer? This is impossible now to say, but circumstances militated against him. Mr. Price died, in part, due to what Michael Balint famously called ‘the collusion of anonymity’—when no one health care provider takes charge and, as a consequence, the patient declines due to neglect and oversight. “The centre cannot hold,” as T.S. Eliot wrote, “Things fall apart.” So it was for Mr. Price. It may have cost him his life.

One can say the system was at fault—and it certainly was in this case. But if one physician had stood up for the patient, had acted as his advocate, the fatal outcome might have been prevented. The fact that no one did is truly remarkable. Whose fault was this? There was a shared irresponsibility: for example, the DOT MD could and should have followed up with Mr. Price. The walk-in clinic MD could and should have arranged for someone to follow up on his concerns, as regards Mr. Price. Radiology could and should have arranged the CAT and made sure that both the patient and his doctor understood the seriousness of the findings on ultrasound.

Unfortunately, no one was there to act as Mr. Price’s advocate and to ensure his best interests were served and that he received care in a timely way. This is the role of a family physician—to know his/her patients well and to be on the phone and raising a ruckus, especially when a patient has a potentially serious and treatable condition.

Mr. Price’s death is, hopefully, not in vain. It did result in a 2013 provincial inquiry into his death. This focused on the lack of continuity of care and on the need for a province-wide shared EMR. Having patients fully informed and involved in their care could help prevent such events from recurring. The inquiry made a series of recommendations that the new provincial government has promised to review.

A mechanic once said of the aging Sea King rescue helicopter. “It’s not an aircraft,” he said. “It’s 10,000 parts flying in close formation.” This is the health care system in Canada.

All MDs should listen to or read about this case. We, as individual practitioners, can and do make a difference to the lives of our patients. A shared health care EMR across a province might have helped Mr. Price. But I cannot help but conclude that the most important element to getting and giving good medicine is having a dedicated caring health care professional to act as the patient’s advocate and to ensure that what is in a chart is acted on in a timely way. Failing that human interface, no computerized system will make the needed difference.

A focus on care after treatment

Dr. Margaret I. Fitch, RN, PhD

Within the cancer care system, we have never been at the point we are at present in regards to the number of individuals who have been diagnosed and treated for cancer and who are living longer with controlled disease or no clinical evidence of disease. And this cadre of individuals is growing day by day, as advances in science and technology contribute to the early identification and treatment of cancer. This situation places us in an excellent position to learn from these individuals where there are gaps in care and to explore ideas for improving care delivery and support.

One gap that has been identified through a number of studies and stakeholder forums is the lack of information about what will happen after treatment has been completed. Patients or survivors have indicated very little, if any, information was provided to them about what will happen once their primary cancer treatment has finished.

For many individuals, concerns abound regarding a number of questions: Is the cancer really gone? When will I know for certain if it is gone? Will the cancer come back? How will I know if the cancer is back? What should I be watching for to know if it is coming back? Fear of recurrence is a clearly identified phenomenon within this population, but varies in intensity from person to person. It can reach high levels where the emotional distress becomes immobilizing and referral to a psychosocial expert would be beneficial.

Furthermore, many individuals wonder what can be done to prevent—or at least reduce the chances of—recurrence. They want to know what they can do themselves. The end of cancer treatment is often a time when individuals are motivated to make lifestyle changes (e.g., diet and nutritional choices, physical conditioning and exercise, smoking cessation).

In speaking with individuals following their cancer treatment, many described how little information was provided to them about what is to happen following their treatment or what they can do themselves in going forward. At best, they indicate they were given a list of future appointments with their oncologist and an indication about when some follow-up tests would be advisable (e.g., often surrounding the time of the appointment). Occasionally the list was written and they took it home with them. Most are not aware of what information is shared with their family physician about their cancer treatment or expected follow-up activities unless they take responsibility and share the information with their physician themselves.

What many individuals are calling for, at the end of their cancer treatment, is a clear idea of what will happen next. They would like to know what will happen to monitor their disease status, what do they come back to the cancer centre for, what is the family doctor responsible for, what side effects do they watch for, and what do they do if side effects emerge. Additionally, they would like to know what community resources are available and how they can contact or access these resources.

A written document containing all this type of information has been labelled as a survivorship care plan. It can be offered as a paper-based or electronic document. The end result is a plan for the individual patient or survivor that is in his or her own hands and can be shared with their personal family doctor. The information is tailored or based on the disease type and stage and the treatment the individual actually received. The late and long-term side effects to watch for are a function of the treatment that was actually received.

At present, very few Canadian cancer centres or programs are offering this type of comprehensive written plan. Early evaluations of pilot projects regarding survivorship care plan use in Canada indicate receiving such a plan can be helpful in reducing uncertainty and unease for the individual survivor and result in an increased sense of knowing what to do and being in control. Providing the plan during a transition appointment (focused conversation about after care and what is to happen at the end of treatment) facilitates the person’s understanding of the plan and the roles of various health and cancer care team members. This is especially the case for clarifying the roles of the oncologist and the primary care physician. Finally, having a clearly identified mechanism for patients/survivors and their primary physicians to contact the cancer centre or program, should a question or problem arise, is seen by survivors as reassuring.

Note: These comments were based of pilot projects funded by the Canadian Partnership Against Cancer to evaluate the use of survivorship care plans in a Canadian environment. See www.canadianpartnershipagainstcancer.ca
Metastatic non-small cell lung cancer (mNSCLC) patients have a poor prognosis. Erlotinib improves progression-free survival (PFS) and RECIST response rates in mNSCLC patients, but caused toxicities leading to dose reductions. The survival impact of dose reductions is unknown. Various models have been constructed to explain the exposure-efficacy relationship of erlotinib. However, their application to define dosing strategies to optimize efficacy is limited.

A disease progression model of erlotinib predicting PFS of mNSCLC patients was constructed, consisting of a pharmacokinetic component characterizing erlotinib population pharmacokinetics, a pharmacodynamics component describing the concentration-kill-constant relationship, and a tumour growth component tracking tumour size over time. This model was fit against clinical trial data to simulate mNSCLC patients’ PFS and externally validated with other studies. The validated model was used to determine the effect of dose reductions on PFS and the minimum effective serum erlotinib concentration.

The disease progression model simulated placebo and erlotinib patients’ PFS with 0.74–9.14% and 0.26–19.83% error respectively during internal validation. In external validation, it simulated EGFR-mutant and EGFR-wild-type patients’ PFS with 11.3% and 16.7% error, respectively. It predicted significant PFS decreases with dose reductions in both EGFR subgroups. Furthermore, the model predicted that the minimum serum erlotinib concentration required to achieve at least a partial response is 2 mg/mL.

This is the first population-based disease progression model that robustly predicts PFS in mNSCLC patients on erlotinib. Future research will be focused on constructing a therapeutic drug monitoring program to predict outcomes at the patient level.

Clinical trials update: SC.24 Opened

**Dr. Sten Myrehaug, MD, FRCP**, Department of Radiation Oncology, Odette Cancer Centre, Sunnybrook Health Sciences Centre

The Department of Radiation Oncology is pleased to announce the opening of NCIC-CTG SC.24, a phase II randomized feasibility study comparing stereotactic body radiotherapy (SBRT) versus conventional palliative radiotherapy (CRT) for patients with symptomatic spinal metastases. Our department has a significant administrative involvement with this trial, with Dr. Arjun Sahgal being the national study chair and Drs. Young Lee and Sten Myrehaug being the quality assurance leads.

Vertebral body metastases are common in clinical practice. Although increasingly being adopted as a therapeutic option, SBRT for these patients has never been addressed in a phase III clinical trial. SC.24 aims to determine the feasibility of accruing to a randomized study, with aims of leading to a phase III investigation. Primary endpoint is the ability to accrue to a randomized trial, with secondary endpoint assessment of pain control, radiographic/clinical control and quality of life.

In order for consideration of enrolment in the trial, patients must be >18 years of age, have histologic confirmation of malignancy and be ECOG 0-2. Patients must not have had previous surgery or radiotherapy to the intended treatment site, and no chemotherapy can be given within one week of radiation delivery. As pain control is an endpoint, the patient must have a pain score >2 within the intended vertebral body treatment field. No patients with clinical or radiographic evidence of spinal cord compression or mechanical stability should be enrolled on trial, and a maximum of three contiguous vertebral body metastases may be treated.

All patients require a pre-randomization spine MRI, and will complete pre-treatment pain diary and quality-of-life assessments. Following treatment, pain diary and quality-of-life scores will be captured at four weeks and at three and six months. Full spine MRI will also be done at three and six months, at which point clinical trial follow-up is complete.

If you have a patient you think may be eligible for enrolment on trial or would like further information, please do not hesitate to contact any member of the spine team (Arjun Sahgal, Hany Soliman, Sten Myrehaug) or our clinical research associate, Hyla Okorofsky.
Supportive care is essential care: A caregiver’s story

Susan Puff, Co-Chair of the Supportive Care Working Group, Manisha Gandhi, MBA, Manager of Patient and Family Support Program, Anya Todici, MBA Candidate, Odette Cancer Centre, Sunnybrook Health Sciences Centre

Susan Puff is an active member of the Patient and Family Advisory Council, co-chairing the Supportive Care Working Group. Her husband Ross was diagnosed with advanced kidney cancer in 2008, with Susan by his side throughout his cancer journey. She presented her story late last month at Grand Rounds, addressing the health care team at Odette Cancer Centre.

The Odette Cancer Centre has a hidden jewel—so hidden that some of you don’t know about it, some of you know just a little bit about it, and some patients and family members either don’t know about it at all or have passing knowledge. The hidden treasure that I’m talking about is the Patient and Family Support Program.

It’s that department that’s tucked in the lower level, across from the cafeteria. Behind those doors is a world of expert care waiting to help each of you to ensure that you are providing the best possible care for your patients and their family members. Until I joined the Patient and Family Advisory Council, I had no idea what was behind those doors, and I wish I’d known earlier.

My husband Ross was diagnosed with cancer at the age of 43. We were given two years, but because of the expert medical treatments that he received from our Odette team, we got four years. For that I’m so very grateful. However, trying to manage those four years, especially that last year, was a tremendous challenge. My husband was a fighter. He went to work right up until he died. He wanted to ensure that the time we had together was as fulfilling as possible. He still wanted to laugh and live. To make this happen meant that we had to manage a lot of things on our own.

In the last year of Ross’ life alone, we had to deal with him throwing up most of what he ate—that went on for more than 200 days straight. He had almost 24 hours of back-to-back surgeries to remove part of a tumour that had spread to his spine. After seven days in the hospital he was able to come home, but that meant that I had to ensure his physical safety and well-being. My husband was just over six feet tall, and although I’m not a will-o’-the-wisp, it was difficult and honestly frightening.

Reflecting back, I know we would have greatly benefited from the help of a dietitian, perhaps a physical therapist, and perhaps a small amount of post-surgery home care. However, by that point, we were treading water; desperately trying not to go under. It didn’t occur to me to discuss the issue with our medical team. I didn’t want to bother them with things that I thought were solely my responsibility to look after for my husband. I didn’t realize that the answers to some of our challenges were available right here at Odette.

Behind those doors are people who are experts in the areas of nutrition, physical therapy, financial matters, including drug payments and estate planning, home care, and so much more. And yes, there are also experts who will help with the emotional stresses that cancer patients and their families have to endure.

Without really knowing about the program and what it offered, Ross and I muddled through on our own. For me, I kept my armour at full strength—whatever needed to be done, I would figure it out. I kept that up for four years and then, when Ross died, I kept my armour at full strength for the first year without him. Then my armour cracked, then it shattered, and then I was completely defeated. I’ve spent the past two years with a psychiatrist repairing all of the damage and gluing my armour back together.

If you endorse and embrace the Patient and Family Support program then so, too, will your patients and their families. You need to recognize how much trust your patients and their people have in each of you. A more beneficial course of action is for each of you to start incorporating the Patient and Family Support Program into your overall treatment programs. I’m asking each of you to start today and I’m asking you to never stop.

This program also can’t be brought forward to a patient and family member only once or twice. There are times in the course of treatment when both patients and their families listen to what you are saying, but not all of it is retained. We try, but sometimes there is just so much to take in that information falls through the cracks.

I’m counting on you to uncover the Odette’s hidden jewel and use it for all it’s worth—every one of your patients and the people who love them will thank you from the bottom of their hearts.

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Continuing Medical Education

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- March 9–12, 2016. 2016 AAHPM & HPNA Annual Assembly. The premier educational event for hospice and palliative care providers, Chicago, IL.
- March 22, 2016. NETs Speaker Tour featuring Dr. Simron Singh. Restaurant Le Pois Penché, Montréal, Quebec. www.oncologyeducation.com/events/upcoming-events/nets-speaker-tour-2016/nets-speaker-tour-2016-home/
- October 7–11, 2016. ESMO Copenhagen, Denmark. www.esmo.org/conferences/ESMO-2016-congress

CME Courses

- Navigating Later Lines of Treatment for Advanced Colorectal Cancer: Optimizing Targeted Therapies to Improve Outcomes. This case-based course presents systemic therapy options available for metastatic colorectal cancer beyond the first-line setting, as well as the current utility of predictive biomarkers in the disease. This activity is an Accredited Group Learning Activity (Section 1), as by the Maintenance of Certification program of The Royal College of Physicians and Surgeons of Canada, for 1.0 MOC. This activity was approved by the Canadian Society of Internal Medicine. Register and visit the CME portal for more information. www.oncologyeducation.com
- New course available! Optimizing Outcomes in Advanced Prostate Cancer. This course will provide an update in prostate cancer, as it pertains to disease heterogeneity and mechanisms of androgen receptor resistance, sequencing of drugs in metastatic castrate-resistant prostate cancer, and will also discuss recent guidelines and current management practices. Register and visit our CME portal for more information. www.oncologyeducation.com