A question of care

Experience

Expérience

Henry Comor

In Brief

The physicians and nurses who care for Canada's cardiac patients are highly regarded for their technical competence. However, Henry Comor wonders if they now place too much emphasis on the science of medicine and too little on its art. His observations follow a quadruple bypass operation.

En bref

Les médecins et les infirmières des unités de soins cardiaques au Canada sont réputés pour leur grande compétence technique. Henry Comor se demande s'ils n'accordent pas toutefois trop d'attention à la science et pas suffisamment à l'art de la médecine. Ses réflexions sont le fruit d'un séjour à l'hôpital pour un quadruple pontage aortocoronarien.

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Depend upon it, Sir, when a man knows he is to be hanged in a fortnight, it concentrates his mind wonderfully.
— Samuel Johnson in a letter to James Boswell, Sept. 19, 1777

Almost 220 years later, I am able to affirm that Mr. Johnson's observation is equally applicable to a prospective quadruple bypass patient. I had a 16-year history of coronary heart disease and knew enough to realize that angina at rest was a signal to call my cardiologist. He ordered an immediate angiogram.

The procedure took more than an hour, during which the anatomy of my coronary arteries was examined from every angle. The tape was rolled back several times so the specialist could confirm what was apparent at first glance: the left main coronary artery was almost completely blocked, the right was totally blocked and there were two other significant blockages. Perhaps because of his patience and concern, I was somewhat numbed to the reality of my situation. I watched the screen as if we were talking about somebody else, some other man who had to choose between surgery and imminent death.

Searching for answers

When we are young, everything has an answer, every problem has been solved. Of course, *we* don't know the answers, *they* are in the teachers' heads or in their textbooks. The sole purpose of going to school, in that glorious world of certainty, was to transfer the answers from teachers to us by whatever methods they saw fit. In my day, 60 or more years ago, those methods could be painful.

As we grow up, we start to realize that some questions have no answers. Even more unsettling is the occasional discovery of a situation for which the question hasn't even been asked. As I was being returned to the hospital's observation unit, only vaguely aware of the sandbag pressed to my right groin, new questions tumbled over themselves, pushing feverishly at my brain, searching for answers that *had* to be there, as if it was my teacher's textbook. The questions were, like life itself, full of paradox and emotions. Many could not be expressed, perhaps

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because they had formed before I had the words to describe them.

They had to do with survival and death, the struggle for one against the inevitability of the other. It seemed important to remain outwardly calm and confident, but I knew there were things that *had* to be done if order was to be restored to chaos.

My efforts to shut down the turmoil were made much easier by the nursing care at the observation unit. Without exception, it was a model for nursing anywhere. I was treated with care and compassion that combined efficiency with kindness and professionalism with concern. One of the nurses told me that because enough money had been dedicated to the unit, there were enough nurses to allow each of them the time to practise their profession without limitation. They were, in her words, "happy to be there."

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I don't remember what I said to my wife. We held hands tightly, 38 years of marriage resisting all efforts to pull us apart. Words were spoken but they were unnecessary. It was as if we stood together — she stood, I lay — ready to face the reality of the moment.

Fifteen minutes later my own cardiologist, having examined the tape, came to see us. He stood at the end of the bed holding my toe, a practice I had learned from the dean of clinical medicine at the Manchester Royal Infirmary, Sir Harry Platt. It was the action of a caring and attentive doctor. His explanation of the diagnosis and prognosis was concerned and compassionate. At my suggestion he agreed without reservation to get a third independent opinion, and did so immediately. Of course, none of us thought a third or a thirty-third opinion would change anything. And it didn't.

Preparing to die

Although he wanted to admit me immediately, he agreed to let me go home for the weekend. During those 3 days I sorted my papers, rewrote my will, wrote letters to my children to be opened only if I died, and drafted daily bulletins for my daughter to record on our answering machine so my wife wouldn't have to repeat everything to callers over and over again..

I see now that I was planning more for my death than my recovery, a fact that can only be understood by knowing something of my personal history. Forty-two years earlier, my father died in my arms 5 hours after his first and unsuspected heart attack. In those days there was nothing to be done in the first few hours other than the administration of opiates or other analgesics. His last words were "I'm sorry. I failed you."

I internalized them to mean that I had failed him. I couldn't do what I was supposed to do. I couldn't save his life. He was 48 years old. As a result, I too was convinced I would die before I was 50. The fact I had managed to live to my mid-60s made no difference: justice might have been delayed, but it wouldn't be denied.

My focus on death continued in the hospital. The surgeon, the anesthetist and the resident cardiologist were attentive and answered all my questions, except one. They all seemed totally unprepared for a patient who wanted his instructions followed in case he died. There were consent forms to be signed, both about the operation and the use of excess tissue for research. These I signed willingly. However, if I died during or after the operation I wanted any useful organ used and my body donated to the medical school.

Neither doctors nor nurses seemed able to deal with this request. To be kind, this reluctance may have been related to an unspoken understanding that the issue of *Death* is not to be raised aloud (except in passing when getting informed consent), but I don't think so. It just didn't seem to be part of the formula, the steps that have been carefully worked out to prepare patients for surgery. The trouble with formulae is that they sometimes do not leave room for unanticipated factors.

In my case, after having been shrugged off 3 or 4 times, I obtained a sheet of paper and wrote out my instructions, had my signature witnessed and gave it to my surgeon, who accepted it with a good deal of embarrassment. My determination was needed — no one on the ward appeared willing or able to oblige me.

The pre-operative lecture

The pre-operative lecture was similarly formulaic, given by a person who had all the words but none of the music. It had obviously been carefully designed and all points deemed necessary had been covered, but I and other patients I have spoken to felt that something was missing (in addition to empathy).

For example, patients' family members are advised to prepare for middle-of-the-night calls to calm their 'loved

one' in the event paranoia is caused by the powerful hypnotics used during the operation. What is not mentioned is the much more likely prospect of nightmares, some more paranoid than others. Six of the 7 patients I spoke with had this experience and were totally unprepared for it.

My repeating nightmare was that I was lying in a trench in no man's land and whichever way I turned someone shot at me. There was no escape. Several weeks after my return home, the dream was easy to interpret: the pain from my chest and leg wounds made it very difficult to rest comfortably. The semi-paranoia caused by the hypnotics made rational thinking difficult, but no nurse would spare the time to talk to me, to ask me what my nightmare was about.

My cardiologist stood at the end of the bed holding my toe, a practice I had learned at the Manchester Royal Infirmary. It was the action of a caring and attentive doctor.

Had one done so, I feel certain the rational explanation would have reassured me. Instead, all they did was attach a purple band to my wrist. I later discovered this was to signal that I was confused and was to be stopped if found wandering in the corridors. (I was, in fact, never stopped, which may or may not say something about the efficacy of the wrist band.)

The medical production line

The nurses who provided immediate postoperative care were beyond reproach. One of the definitions of the verb to nurse is "to cherish," and indeed I felt cherished, comforted and loved. It was, in the true meaning of the term, intensive care. (And the nursing commitment was such that my immediate postoperative nurse, the person whose encouraging voice was the first I heard in the recovery room, visited me twice on her own time.)

But after 24 hours I began to realize that I was on a medical production line. The second day I was moved up to the ward where it appeared that 1 nurse was responsible for 2 patients; the next day my nurse was caring for 4 patients, and the day after 6 or 8. Two days later, I was discharged. My impression may or may not be correct, but the facts leading to the conclusion are inescapable: the level of care deteriorated almost exponentially from day to day.

This was particularly noticeable at night. Patients are settled down as early as possible and then, as far as possible, ignored. Several former patients have confirmed my experience that calls for assistance were treated as something of a nuisance. In my case, the heparin lock backed up twice, causing swelling and pain. Both times my complaint was given a cursory look and ignored. Neither was changed until the next day and the resulting bruising did not disappear until a week after I had returned home.

On the third day, the wound in my leg split open from top to bottom. Both it and my chest wound appeared to be infected. I was quickly attended to by the resident cardiologist, who prescribed an immediate course of antibiotics. This happened before 9 am; when no antibiotics had appeared by 3 pm, I asked a nurse about the delay and was told the prescription had not yet been received. At 4 pm, I was informed that the dispensary was often late in delivering prescriptions. An hour later, I discovered that the clerk waited to the end of the day to send all prescriptions downstairs at once.

When I expressed my shock and made a vigourous protest, the prescription was retrieved and sent to the pharmacy. A patient is normally ill-equipped to judge the quality of medical care given by the nursing staff, but in my case it was obvious that rapid treatment was necessary, if only to ease my state of mind.

I understand that the mandate of facility where I was treated is "the pursuit of excellence." There is no doubt that, technically and technologically, this institute is at the cutting edge. But I can't help observing that because of financial constraints there has also been a pursuit of greater efficiencies, some of which appear to have been inspired by a philosophy propounded at the Harvard Business School. My impression is that very little thought has been given to the emotional impact of heart surgery. I had been taught that medicine was an art as well as a science. As in other areas of modern life, the art appears to have taken a back seat.

The irony is that, as far as I can see, none of my criticisms have much to do with money. It is as if, in the search for greater efficiency, the heart is sometimes missing from heart care.

Where's the empathy?

When I was a medical student, I was warned not to become emotionally involved with my patients. As self-protection that was probably good advice, but emotional involvement is now considered synonymous with empathy.

Clearly, this is not the case. Empathy means comfort, compassion, sensitivity, solace and understanding, qualities that are essential for any doctor, nurse or caregiver. For patients who have undergone the trauma of heart surgery, a lack of empathy from a physician or nurse can easily be interpreted as its antonym: hostility.

In contrast, much of what is attempted during cardiac rehabilitation concerns the 'art' of medicine. My experience has reminded me that everything cannot be reduced to quantitative analysis. Yes, they measure blood pressure, monitor body weight, record cholesterol and triglyceride levels, time lap speed and count pulses, but they also make time to listen. And in both the groups I have been privileged to participate in, almost everyone not only wanted but also needed to talk. What I heard were stories of life, rich in diversity, that crossed the boundaries of time and place. And out of such talk came the healing balm of shared laughter.

The participants are not lepers to be isolated — they are unique individuals brought together by common interests. How do I reconstruct my body image that has been so severely damaged? How do I cope with the emotional trauma? Many cardiac patients have lived their lives ruled by the clock. In rehabilitation, I came to realize that in every group the most powerful force is the dynamic of the journey being taken together. Each of them has come face to face with mortality. They join together, and in doing so restore their faith in humanity. They are, to use the words of John Milton:

Untwisting all the chains that tie
The hidden soul of harmony.

Questions still remain. What have I lost? What have I gained? Who am I now? These are not questions unique to me. At one local hospital 6 psychiatrists, all recovered bypass patients, have an unofficial Zipper Club and meet once a month as a self-help support group.

Most of us must fend for ourselves. I thought it might help me to write a critique for the board of the hospital. My cardiologist, the toe-wiggler, told me it read like a buyer's guide, which proved that he's a smart editor as well as a good doctor.

A few days ago another question occurred to me. I asked a physician friend whether medicine is still a caring profession.

"It had better be," he replied, "or we're out of business."