CONSUMERS' VIEW

My adventures as a hospital patient

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For the first time in many years I entered a hospital not to ask questions and to make recommendations but to undergo a quadruple coronary bypass. Aside from the time spent under anesthesia, I found myself for the next two weeks asking questions and making recommendations.

There had been some dark patches. By the time I had been moved into the intensive care unit I was in a deep depression, with all the attendant distortions of perception and affect. I had *not* been warned about this, nor was any help given in dealing with it. I was hearing voices, seeing sounds, and completely disoriented. It felt like a bad trip. A fellow patient in an adjoining room was even worse off; he spoke only of suicide. Yet the hospital did nothing for him. He refused to stay in the hospital and it was left to me to talk with him and hold him together until his family arrived to take him home. To my surprise I learned that all the staff were aware that patients coming out of the operation were almost invariably depressed. The

failure to communicate and to warn was standard procedure. One wonders what would have been said if the prospective suicide had carried out his plan. They probably would have said "poor chap, he lived a good life. We could not have stopped it . . ."

The first thing of importance is not to expect a true and complete account from a patient after he has left hospital. Family members recall my saying "the first night on the ward was appalling, the second merely abominable". By the time I was released I had fortunately completely forgotten those perceptions.

I do not know exactly what happened during the surgery itself. I have begun to have some doubts about the skill with which my leg veins had been stripped for use in the bypass as I continue to suffer from leg swelling 12 weeks after the operation. I was told later that the veins from the first leg were "unsuitable" so the other leg had to be opened as well. There are significant differences in the states of the two legs and I suspect that a different hand had done the second, and in a hurry. Lacking a video record I probably shall never find out what actually happened.

Two family members took turns attending almost continually during the first 3 or 4 days following surgery. It would appear that I was not an easy patient for the nursing staff (see comments by family members).

Towards the end of my stay I became more mobile and wandered about the floor getting my mandatory exercise. I noted with interest the device used to hold patient identity

Box 1 Reports of family members

Report of family member #1

"He requested to see the medication order book before each medicine was delivered. He requested quite often that two nurses independently read the medication order. On one occasion he commented, quite correctly, that the hypodermic needle was poorly designed with a high probability of error.

Food service staff were not informed of medical orders. In one case, before a test procedure there was a sign "nothing by mouth" yet a tray was delivered to him and caught just in time by a family member.

Frequently, food or drink specifically ordered *not* to be given was sent up. No one seems to check on what or how much a patient eats. On the only evening when a family member was *not* present during meal service he ate nothing. The tray had been put too far away to reach. It was taken away, untouched, by the attendant, no attention having been paid to the fact that the patient had not eaten. A family member was present at all meal services after that."

Report of family member #2

"The whole set-up appeared to be a compounding of ongoing procurement failures (failures to have or find), infrastructural failures (failures of function), social-structural (failures to act), and classical errors. Although I did not take notes at the time, and so have reason to suspect my recollections, this is what I saw and still remember:

- Procurement: valve and regulator for mobile oxygen units non-functioning. Nurse and visitor worked, without success, to assemble a working unit from old pieces in storage. New regulator eventually procured from another wing.
- Infrastructural:
 - (1) non-functioning paper dispenser in bathroom;
 - (2) bed controls and nurse call out of reach of patient.
- Social-structural: non-response to patient's urinary distress. Doctors did not offer assistance even under direct appeal from patient.
- Errors:
 - (1) oxygen left on even when not used by or connected to patient;
 - (2) oxygen line to patient connected, in substitution error, to vacuum line (corrected quickly);
 - (3) insulin delivery to wrong room, wrong patient;
 - (4) mobile x ray unit brought to patient in error; patient had been brought to x ray less than one hour before."

cards. It was identical with the one that had figured in an earlier investigation in which a wrong transfusion led to the death of a patient due to mistaken identity. In 1999 I had spent a significant amount of time in another related hospital, investigating an accidental death stemming from patient misidentification. It was clear that the wrong card had been used to print the labels for the blood to be sent to the laboratory for typing. When patient B was in surgery multiple units of blood (patient A's type) were sent to the operating room and infused into patient B. B eventually died. The card selection error was easily performed, given the design of the card holder. Apparently the first hospital had not informed the other hospitals of the danger of the defective card holder.

By the time I was ready to leave, nurses and doctors alike had become exceedingly careful and answered my questions about my own treatment almost too thoroughly. I often had no need to ask—information flowed to me. Medications were shown to me and explained before they were injected or given to be swallowed. In short, the staff were doing what I had long felt would be the best way to run a hospital—engaging the patient as the final defensive barrier against error. It was clear that I was a customer whose well being and satisfaction were necessary for the well being of the hospital.

When I left I thanked the staff for their excellent treatment and care and apologized for having been a difficult patient. I was assured that I had not been difficult (patently false) and that they had learned a great deal from me (probably true). I was deeply gratified. I had made some improvements in patient safety merely by being a patient and following my own survival instincts!

As it happened, I was quite unaware of what events had occurred immediately following the surgery. The reports of other family members are more revealing (see box 1). The presence of the family members during the first 2 days after surgery was very important. They watched and guarded when I could not do that for myself. We had not thought of keeping meticulous notes. Next time—if there is a next time—that will be added. Of equal importance is the preservation of the dignity and authority of the patient. I refused to be addressed by my first name; I insisted on knowing everything that was to be done before it was done; I made my discomforts known. All patients should be instructed to be aggressively self-defensive. It gets the attention of hospital staff and keeps them alert to the patient's safety as well as to his or her needs.

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COMMENTARY

Admitting to *schadenfreude* is a shaming experience, especially when the malicious delight that one is taking in the shortcomings of a healthcare provider which has been lauded as being of better quality than most in the Western world inevitably means one is appearing to take equal delight in a patient's misery.

Let me therefore spell out my precise reactions to Professor Senders' story. First, as one who spends much time working with UK hospital managements, I found comfort in hearing that Canadians—superb though we all know their health service to be—have the same problems that exist here in the UK. However, as one who also works closely with patients, support groups, and who has been a patient herself on far too many occasions, I found myself saddened to read of a patient going through the same tiresome hassles many of us experience here.

Food being delivered to the bedside but not to the patient is a case in point. Professor Senders, I have no doubt, left hospital a deal thinner than he was when he went in—and some of that weight loss was due, it is virtually certain, not to the effects of his disease and its treatment but to the failure of the hospital to pay sufficient attention to an area of care that may seem—when compared with delivering miracles of surgery and amazingly powerful and complex modern radiotherapy and drugs—to be very small potatoes.

The decision by the family that a relative should be present at every meal service after one meal had been placed so far away from Professor Senders that he couldn't reach it, and had been taken away untouched with no staff member seeming to care, rang loud bells with me. The same complaint has been made in UK hospitals for years, ever since overseeing patients' meals ceased to be the responsibility of nurses, but an attempt is being made to set up a new system that will make sure patients not only get better nutrition but also pleasure from it. Loyd Grossman heads a panel that is working hard to design better menus and better delivery methods. As a member of the panel, I have high hopes that it will make a real difference—providing the Department of Health is prepared to put some muscle and money behind the recommendations. Maybe the action of Professor Senders' family gave a similar idea to the staff in Toronto? If not, they could—as interested observers—suggest that the hospital finds out from the UK NHS what can be done in this area.

I was enchanted to discover that Professor Senders himself, once he was mobile around his ward, was able to investigate the matter of patients' identity cards. Here he acted as an information conduit, passing information from one hospital to another that should of course have been disseminated to every other hospital in the country. Professor Senders' surgeons and the hospital may have saved his life, but he more than recompensed them. It is exceedingly likely that his observation and knowledge of a potentially dangerous system in use in his ward has saved future lives from accidental loss. Are we in the UK any better at checking our basic ward systems and seeking to redesign them when necessary? Do we make sure that every other hospital is warned of any such problems we discover and offer our remedies? Of course we don't. We're supposed to share information but it is one of the rules more celebrated in their breaking than in their keeping.

Professor Senders was clearly what was known in my nursing days 50 years ago as a "ward treasure". Our patients stayed in hospital far longer after treatment than they do now. We could usually count on having three or four convalescent and blessedly ambulant patients to help us when we were hard pressed, especially at night. Sending one of them to sit with and encourage and support a depressed patient was common practice. After all, we had no available treatment for depression apart from that sort of human comfort which was precisely what Professor Senders offered his fellow patient out of his own basic wisdom and good heart (which no amount of surgery could diminish).

Professor Senders feels there should be preliminary discussion with patients about this aspect of surgery (and all too well do I know the way a black pall descends almost as soon as the fumes of the anaesthetic wear off), and it is a thoughtful point. Some doctors and nurses do; others avoid it for fear of making a self-fulfilling prophecy that, if you tell a patient depression might happen, then it will.

All of Professor Senders' comments were valuable and his hospital should invite him and other observant intelligent patients to act as members of a patients' forum that could feed back useful information about patient experience. Systems and methods could then be changed accordingly to everyone's benefit. Even more importantly, it would help to make staff behave with all patients in the way in which they eventually behaved with Professor Senders—that is, with great care, checking the medication book with him whenever he was

given any dose, explaining everything, and answering all his questions courteously.

Why isn't it like that for every patient, however intelligent or otherwise they might be? Simply because staff are usually overburdened and rushed and if they can cut corners, they will. A highly informed and demanding (not a pejorative word, but strongly approving in this context) patient like Professor Senders improves professional and individual practice hugely for the better. People like him and his family are a priceless resource for any system of health delivery. They

should be brought on board as much as possible once they are well again so that every patient gets the care Professor Senders got eventually as "a customer whose well being and satisfaction were necessary for the well being of the hospital".

I agree with his suggestion that we, the patients, should be strongly self-defensive. No one else would do the job better.

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Box 2 Patients' survival kit: 20 tips to help prevent medical errors

What are medical errors?

Medical errors happen when something that was planned as a part of medical care doesn't work out, or when the wrong plan was used in the first place. Medical errors can occur anywhere in the healthcare system: hospitals, clinics, outpatient surgery centers, doctors' offices, nursing homes, pharmacies, patients' homes.

Errors can involve medicines, surgery, diagnosis, equipment, or laboratory reports and can happen during even the most routine tasks, such as when a hospital patient on a salt-free diet is given a high-salt meal.

Most errors result from problems created by today's complex healthcare system. But errors also happen when doctors and their patients have problems communicating. Uninvolved and uninformed patients are less likely to accept the doctor's choice of treatment and are less likely to do what they need to do to make the treatment work.

What can you do?

(1) The single most important way you can help to prevent errors is to be an active member of your healthcare team—that is, taking part in every decision about your health care. Research shows that patients who are more involved with their care tend to get better results. Some specific tips, based on the latest scientific evidence about what works best, follow.

Medicines

(2) Make sure that all your doctors know about everything you are taking. This includes prescription and over the counter medicines, and dietary supplements such as vitamins and herbs. At least once a year bring all of your medicines and supplements with you to your doctor. "Brown bagging" your medicines can help you and your doctor to talk about them and find out if there are any problems. It can also help your doctor to keep your records up to date, which can help you get better quality care.

(3) Make sure your doctor knows about any allergies and adverse reactions you have had to medicines. This can help you avoid getting a medicine that can harm you.

(4) When your doctor writes you a prescription, make sure you can read it. If you can't read your doctor's handwriting, your pharmacist might not be able to either.

(5) Ask for information about your medicines in terms you can understand—both when your medicines are prescribed and when you receive them.

- What is the medicine for?
- How am I supposed to take it, and for how long?
- What side effects are likely? What do I do if they occur?
- Is this medicine safe to take with other medicines or dietary supplements I am taking?
- What food, drink, or activities should I avoid while taking this medicine?

(6) When you pick up your medicine from the pharmacy ask: "Is this the medicine that my doctor prescribed?" A study by the Massachusetts College of Pharmacy and Allied Health Sciences found that 88% of medicine errors involved the wrong drug or the wrong dose.

(7) If you have any questions about the directions on your medicine labels, ask. Medicine labels can be hard to understand—for example, ask if "four doses daily" means taking a dose every 6 hours around the clock or just during regular waking hours.

(8) Ask your pharmacist for the best device to measure your liquid medicine. Also, ask questions if you're not sure how to use it. Research shows that many people do not understand the right way to measure liquid medicines—for example, many use household teaspoons which often do not hold a true teaspoon of liquid. Special devices like marked syringes help people to measure the right dose. Being told how to use the devices helps even more.

(9) Ask for written information about the side effects your medicine could cause. If you know what might happen, you will be better prepared if it does, or if something unexpected happens instead. You can then report the problem right away and get help before it gets worse. A study found that written information about medicines can help patients to recognize problem side effects and then give that information to their doctor or pharmacist.

Hospital stays

(10) If you have a choice, choose a hospital at which many patients have the procedure or surgery you need. Research shows that patients tend to have better results when they are treated in hospitals that have a great deal of experience with their condition.

(11) If you are in a hospital, consider asking all healthcare workers who have direct contact with you whether they have washed their hands. Hand washing is an important way to prevent the spread of infections in hospitals, yet it is not done regularly or thoroughly enough. A recent study found that, when patients checked whether healthcare workers washed their hands, the workers washed their hands more often and used more soap.

(12) When you are being discharged from the hospital, ask your doctor to explain the treatment plan you will use at home. This includes learning about your medicines and finding out when you can get back to your regular activities. Research shows that, at discharge time, doctors think their patients understand more than they really do about what they should or should not do when they return home.

Surgery

(13) If you are having surgery, make sure that you, your doctor, and your surgeon all agree and are clear on exactly what will be done. Doing surgery at the wrong site—for example, operating on the left knee instead of the right—is rare. But even once is too often. The good news is that wrong site surgery is 100% preventable. The American Academy of Orthopaedic Surgeons urges its members to sign their initials directly on the site to be operated on before the surgery.

Other steps you can take

- (14) Speak up if you have questions or concerns. You have a right to question anyone who is involved with your care.
- (15) Make sure that someone such as your personal doctor is in charge of your care. This is especially important if you have many health problems or are in a hospital.
- (16) Make sure that all health professionals involved in your care have important health information about you. Do not assume that everyone knows everything they need to.
- (17) Ask a family member or friend to be there with you and to be your advocate (someone who can help get things done and speak up for you if you can't). Even if you think you don't need help now, you might need it later.
- (18) Know that "more" is not always better. It is a good idea to find out why a test or treatment is needed and how it can help you. You could be better off without it.
- (19) If you have a test, don't assume that no news is good news. Ask about the results.
- (20) Learn about your condition and treatments by asking your doctor and nurse and by using other reliable sources. For example, treatment recommendations based on the latest scientific evidence are available from the National Guidelines Clearinghouse at <http://www.guideline.gov>. Ask your doctor if your treatment is based on the latest evidence.

General points

For almost every disease there is a national or local association or society that publishes consumer information. Check your local telephone directory. There are also organized groups of patients with certain illnesses that can often provide information about a condition, alternative treatments, and experience with local doctors and hospitals. Ask your hospital or doctors if they know of any patient groups related to your condition. Also, your local public library has medical reference materials about health care treatments.

For further information you may also wish to see *"The Savvy Patient: How to Be an Active Participant in Your Medical Care"* by D R Stutz, B Feder, and the Editors of Consumer Reports Books published in 1990 by Consumers Union of US Inc, Yonkers, NY 10703, USA.

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