Medicine for Managers

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What does a patient need to know?

One of the most challenging and controversial issues in healthcare generally is how much we tell our patients about what is wrong with them and what their options are. There are almost as many opinions as there are clinicians to supply them. Whatever approach people take will be welcomed by some and rejected by others. So what do we say?

There is no doubt that, in theory, you have a shed load of rights in terms of what you can expect from your doctor or any other healthcare professional. The difficulty is that there is huge disparity between what some clinicians wish to inform patients about and a similar huge disparity about what patients wish to know. It is a juggling act which engages every clinician during their whole working lives.

As a medical student I remember doing a ward round with a consultant physician. He was a nice man and a good teacher. The next patient to be seen was a lady with breast cancer.

She was a nun and the tumour was inoperable. The consultant said to us, before speaking to the patient, that it was wise to explain the situation and that the fortitude born out of her religious beliefs would allow her to cope with the news. He couldn't have been more wrong. The news devastated her. She became depressed and persistently tearful. She was inconsolable. A psychiatrist prescribed medication; in those days tricyclic antidepressants which seemed to do little apart from making the patient drowsy.

In hindsight, perhaps all sorts of things could have been done differently. Giving the news without students present, giving just part of the news and providing more in small packets, emphasising any elements of hope or spending more time on the treatments available. Whatever went wrong, for that poor lady it was a disaster.

Only a few years ago, medicine was very paternalistic. Patients didn't ask and doctors didn't tell. And if the patient said "what is going to happen", as often as not the answer was "don't you worry, I'll sort it out for you" and that was all they got.

When explanations were offered, they were often not understood. I sat in, as a house officer, on another physician, a really delightful man, talking to two elderly ladies about the illness of one of them.

He explained slowly and carefully to them the nature of the problem, the treatment and the prognosis. I thought he did it well and in a very kindly manner. The two ladies left and I followed them out of the consulting room. One turned to the other and said "What a clever man, speaking in Latin like that". Perhaps he hadn't done as well as I had thought.

So, should we tell patients everything, or nothing, or should we be selective? Should we tell them everything serious but omit the trivial?

The Chester-Afshar case [2004] involved a lady who had had back pain for a number of years and which was severe, often preventing her from walking and she struggled to control her bladder.

MRI scan revealed a disc protrusion into her spinal cord. The neurosurgeon advised her to have surgery. He did not warn her of the 1-2% risk that the surgery could make the symptoms worse.

The surgery was undertaken; there was no suggestion of any negligence and indeed the view was that Mr Afshar, the surgeon, was highly skilled. However, in this case the surgery was unsuccessful and her symptoms worsened. Mr Afshar argued that he could not warn every one of all the risks, Ms Chester, the claimant, said that, had she known about the risks she would have looked up the information and might have obtained a second opinion and she would have discussed it with family and friends, but she still might well have proceeded to surgery.

The case went to a series of hearings and a trial judge found that the surgeon had not been negligent in performing the operation but that his failure to warn her had been a breach of duty.

Finally the case went to the House of Lords where it was argued that, whatever she had been told, she was likely to have consented to the surgery and, whenever it was done, it would carry the same risks.

The case was considered by five Law Lords. Three found in favour of the claimant, two dissented. The basis of the decision was that the patient had the right to be informed of any small serious risk and that the law protected that right.

One Law Lord said, "*The existence of the duty is not in doubt. Nor is its rationale . . . to enable adult patients of sound mind to make for themselves intimate decisions affecting their own lives*." Another Law Lord said, "*In modern law medical paternalism no longer rules . . . the patient has a right to be informed of a small but well-established risk"*.

This decision appears to have taken medical judgement out of providing information in the sense that there appears to be no alternative to warning of every significant risk however small.

Opponents will say that in doing so there are some patients who will be so frightened that they will not proceed with procedures that they should have.

Equally, to be told all the side effects of even the most benign or vital medicines might result in patients not taking drugs that could render them well and keep them safe from such things as heart attack or stroke.

Proponents will say that it is all in the words and that even bad news can be presented in such a way that it does not appear to be frightening.

It comes back to the recognition that all patients are different and some want to know everything whilst others want to know nothing, even if it means not knowing about potentially serious matters.

If I had only a short while to live I think I would want to know to get my affairs in order. Having said that, would I really? I am not entirely sure.

Some people who know that they have a poor prognosis galvanise themselves to fight and live. Others just wait to die.

Certainly, in my time as a GP, I have often used the escalator system of transmitting bad news to patients and have tried to judge how much to impart at any one time.

So, given a patient with (say) lung cancer who has had the diagnosis but the latest evidence is that the treatment has been unsuccessful, I might say, after usual exchange of pleasantries, "*so I think the latest X-ray was a bit disappointing*".

Depending on whether he enquired about further information or cut the conversation off, I would lead on, in this example, to what had changed, how it had changed, what that meant for symptoms and treatment and, if he wanted it, what the prognosis might be.

If he chose to stop the conversation at any point I would make a note of it so that I would know to where to return on the next consultation.

It seems to have worked for me but different doctors have different systems to give those awkward or distressing facts to an unsuspecting patient.

Sometimes, of course, the patient knows all too well what is wrong and the doctor's explanation is merely a confirmation of what he or she already knew.

The bottom line of this topic, the very kernel of the matter is that any doctor, confronted with a patient requiring information, particularly about a serious problem, may feel it appropriate to give a very little information, some information, a reasonable amount of information, a lot of information or everything he or she knows about the information.

The patient on the other hand may want only the good news, the general indication of the problem, a reasonable amount of information about the condition, its treatment and prognosis, a lot of information or every last detail about the disease.

Get it right and the doctor-patient relationship is sealed and the doctor can do no wrong! Create a mismatch between what the doctor has to say and what the patient wants to hear and it may be reflected in a feeling on the part of the patient that the doctor lacks knowledge, skill, empathy or simply isn't very good.

There is no doubt that telling the patient the right amount of information in terms of the patient's expectations is extremely helpful and it can enhance the physical recovery and facilitate a trust in whatever the doctor may do or prescribe.

Sir William Osler said "*The good physician treats the disease; the great physician treats the patient who has the disease***"** (circa 1884). An astute physician he lived from 1849 to 1919. Like so many of the great 19th and early 20th century physicians, they understood little of pathology but a lot about fear and virtually their only treatment was the kind word and the selective explanation.

Knowledge, technology and facility has burst forth like an explosion of miracles but perhaps communication has actually gone backwards.

Despite rigorous undergraduate training on communication, I do not see many kindly spoken young clinicians.

Perhaps we need to stand up more firmly for the frightened amongst us and free doctors to make more judgements about what people want to know.

But then we all know best, don't we!

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