DISCUSSION: MEDICAL HUMANITIES

The patient - doctor relationship

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Abstract

In this essay I speak about the need to put the patient first when discussing the relationship between the patient and the doctor. From my own experience of having been a cancer patient, I argue that most patients appreciate and feel empowered by knowledge about their illness if this knowledge is given sensitively. I also try to explain why doctors need to recognise and respond sensitively to the patient's need to be healed, psychologically, as well, especially in cases of serious or chronic illnesses.

I would like to talk about the patient-doctor relationship. It's always talked of as doctor-patient relationship but I think one needs to look at it from the point of view of the patient. It is an important relationship when you are ill, perhaps the most important relationship in your life at that point in time.

I have been ill many times, have undergone many surgeries, and had lots of interactions with doctors. Besides deriving comfort and knowledge from them, I have also been very interested in seeing how they deal with patients.

The power equation between doctor and patient can never be equal. Clearly, one feels at the mercy of, not just the doctor, but the whole medical system. One feels like a body that they are taking care of – or, given the degree of specialisation, one ends up feeling that each is looking at a particular organ, and how these organs are put together is anybody's responsibility. That is also because the whole breed of general practitioners (GP) is becoming extinct. The doctor who takes complete responsibility for you is a breed that has completely vanished. Ultimately, it's mainly the responsibility of the patient, who has to look at different aspects of his or her body and decide that it does work cohesively after all with no help from doctors.

The patient and doctor meet under trying circumstances - at least as far as the patient is concerned. The context may be just routine for the doctor. You may have made the choice to meet the particular doctor. Sometimes, of course, the power of choice is missing, and you go to the hospital and have to deal with whoever you meet. The anxiety of the patient is born out of the inequalities inherent in the situation. This is why it's so important to look at this relationship from the perspective of the patient.

I'm a cancer patient and I have been operated on for breast cancer twice, with a gap of 18 or 19 years, and both times it was vital to me that the doctors told me everything. But I

can remember times when the doctors hesitated to tell me something, and I had to reassure them! Doctors often go by what they sense the patients want to know. Should the doctor tell the patient the whole truth?

It is possible that wanting to know as much of the truth as possible is a peculiarity of my own disposition. However, I would like to think that if the doctors confided in you and said, "This is a difficult situation, and this is what is happening to you; I feel that given your participation you can face this with some equanimity and courage" – almost demanding those two qualities as it were – then the doctor could say as much as he intuitively thinks the patient can take, and it will become a more empowering journey for the patient.

I would say that telling the patient everything is a basic requirement, even if the patient is not willing to face the truth. Somehow, the fact that you know the truth, or most of it, gives you a sense of empowerment. Uncertainty and a lack of knowledge somehow multiply the monsters in one's head. It is better perhaps to have a factual and 'true' monster than 10,000 false bogeys. Patients will take it, if they are told with a certain amount of compassion and supported through it. And, in India, there are usually enough relatives to support this process.

Anyway, this whole business of knowing the whole truth may not work – after all, who knows the whole truth? I have myself been treated with tamoxifen and letrozole which counter estrogen. While talking to doctors and consulting the literature, I encountered considerable variation in the recommended duration of treatment, as well as the claimed degree of benefit. So it seems to me that research itself, in cancer or many other diseases, is very fuzzy. There is a lot of uncertainty, and I don't think even the doctors know the whole truth... But I feel it is crucial to lead up to the truth that the patient can live with.

There is another reason doctors need to tell patients as much of the truth as they themselves know. This profile of the newly emerging patient who is Internet savvy, and perhaps has more information, and more potential for misinterpretation, is something which the doctor has to reckon with.

I know that a little knowledge can be a dangerous thing, but even that little knowledge is empowering...

Doctors are a resource, so something like a list of questions prepared beforehand can be very useful. If you have 10

minutes with the doctor, it is illuminating if the patient can ask questions and then have some say in deciding how the whole conversation goes.

Doctors are generally very willing to answer many questions. They see that as a very focused way of giving their attention and care, and even impart medical knowledge when necessary. And that becomes an important way of communicating and building up rapport. A patient can also help in that - it is such a crucial relationship when you are ill.

Thinking of what questions to ask also gives the patient something concrete to do. I think that in situations like this, empowerment is a matter of whether you can at least partially take charge of the conversation or you have to let it happen whichever way the doctor wants it to happen. This seems like a small thing, but it could be big in terms of saying: "Look, I have in some sense taken charge of my illness," and that is important.

In the case of a life-threatening illness like cancer, or a chronic illness like lupus, there is a long-term relationship between a patient and a doctor. They meet at a critical point in the patient's life, the doctor saves your life, there's no way the relationship is anything but deep and sacred. You have a sense of being cared for and nourished - it's much more than just gratitude. This is implicit in such a relationship - many people may not express it in words, they usually bring gifts for the doctor - but it is there.

Being a cancer patient, I had such a relationship with my oncologists. When the cancer recurred, I could draw emotional sustenance from the same doctors. Ten years after the surgery, I could call my oncologist and pick up that relationship from where we had left off.

One is always looking for that rapport. Most middle class patients exercise their choice when it comes to doctors. Maybe we're trying to find a replication of the earlier GP model, where generations of a family went to the same doctor.

When this rapport is missing, I personally believe no healing takes place. Sometimes, doctors don't take cognisance of this psychological dimension in the patient. They either pretend it doesn't exist or are critical of it. I remember when my doctor - the company doctor but also a sort of GP - felt I was unnecessarily panicking when I said I wanted to see an oncologist. He quoted the Sanskrit shloka Samshayo atma vinashyate (Doubt destroys the soul) and threw me out of his clinic. I went to the oncologist, fixed the date for my surgery, then went back to my doctor, and told him that I could not have the surgery without letting him know; that including him was important for my healing. He threw his arms around me, almost with tears in his eyes, and said I was his daughter, and that's why he had said what he did.

I feel sometimes the patient-doctor relationship can go beyond the parameters defined by the illness that first brings them together.

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