

Patient Power

When we use the term “tort reform” and say that we are against it because it is unfair to patients who suffered from preventable medical errors, we are using the wrong mode of expression. When we talk about patient safety in the context of hospitals, doctors, nurses and “harm” to patients, we are missing the point. I have become convinced, in my years forming and serving on the Pennsylvania Patient Safety Authority, that we need to pay more attention to patients as consumers. The Pennsylvania Patient Safety Authority is finally getting the message. The long-term planning, which I have been involved with, is now paying attention to patient empowerment.

We will never truly get a handle on the problem of health care associated infections and preventable harm in hospitals and in the pharmaceutical and medical device industry unless we give patients power. I call this the “patient power” movement.

If patients had enough information, easily accessible and understandable information, about hospitals, infection rates, risks of pharmaceuticals and medical devices, then patients could make choices in a way that would not only enhance health but also would decrease medical costs. Just imagine if patients knew which doctors were safest and in what hospitals’ surgical procedures demonstrate the fewest complications.

Pennsylvania has a very weak patient advocacy system. We do have some fine organizations with marvelous people who are concerned about specific issues. There are organizations addressing AIDS, children’s health, and a variety of other important issues. However, we do not have a robust, well-funded patient advocacy voice in Pennsylvania.

There needs to be a coming together of consumer stakeholders, to meet and discuss how we could create and properly fund a patient advocacy voice. This will directly lead to “patient power,” which will make sure that the courts stay open to legitimate claims, that healthcare choices remain in the hands of the consumer, and that costs are something patients themselves have a right to know about.

I still chuckle about a story in my own family. My father required a new hip because his quality of life had become so poor and he could barely walk. He had heart problems, and had a high risk of any kind of surgery. He met with 3 or 4 different doctors, and he demanded to know what they would charge his insurance company and what the deductible would be. He also demanded information about which hospitals had the lowest incidence of heart-related complications during and after orthopedic surgery. He was persistent, and he obtained the information he wanted. He had his surgery at a hospital with the lowest cost, a very fine and well-respected institution, and with the lowest complication rate. He came out with flying colors, and the quality of his life was much enhanced. People ordinarily do not do that. It is very difficult for patients as consumers to get such information, and it only has become more difficult with time.

We know, for example, that electronic medical records have made the obtaining and understanding of medical records virtually impossible for the consumer. Even doctors complain vociferously about the problem with medical records.

We need to develop an approach to patient power which does not necessarily support any individual institution or power group, but rather which is focused wholly on the interests of patients and what patients need to know and the choices they are required to make.

It is very important that this organization does not fall into the hands of Republicans and Democrats, trial lawyers or medical people. It must truly speak with an independent voice.

We need to seek ways to make this happen. There should be a statewide conference to discuss the issues.

Suggestions would be appreciated. This is an open approach, which hopefully will lead to a consumer-oriented understanding of how patients can not only participate in their own healthcare, but also make informed choices.

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