

Why patients need a say in their health care

As the philosopher in residence at Baycrest, one of the world's foremost geriatric hospitals and research centres, Sholom Glouberman helps patients, family members, health care providers and researchers navigate everything from complex ethical issues to interpersonal and interprofessional relationships.

Now, he is turning his talent for insightful analysis to the broader health system and, more specifically, to the place of the patient in the system.

Dr. Glouberman is author of the new book *My Operation: A Health Insider Becomes a Patient* and one of the founders of the new Patients' Association of Canada.

The book tells of the colectomy (surgical removal of part of the large intestine) he underwent six years ago, as well as the postoperative complications. The time he spent in hospital and in recovery was put to good use.

The Toronto-based philosopher explains how as a patient (and much to his surprise), he became deferent and passive. The care was good – not great – but, worst of all, he was struck by how the patient-provider relationship was totally one-sided.

Customer service was non-existent and communication was abysmal. This is graphically illustrated in the book, where Dr. Glouberman has reproduced his medical records and contrasted them with the personal record of care he kept.

The disconnect between the narrative and the official record is so striking that, at times, it is hard to believe it is the same patient.

It is worth noting too that getting hold of the records was a tremendous

ordeal, even for someone with an insider's knowledge of the system. The pervasive notion that patients have no business seeing their own medical records speaks volumes about what's wrong with our health system.

In the 21st century, it is still "doctor knows best." All too often, patients are not people, they are charts, and they're supposed to shut up and do what they're told.

The patient experience left Dr. Glouberman shaken and he got involved in the hospital's patient committee, where he met others with similar experiences.

They formed a group called GRIPE (Group for the Realistic Improvement of the Patient Experience) that evolved into the Patients' Association of Canada.

"We started out as an angry mob but we've become a group of people determined to make the health system more patient-centred," Dr. Glouberman said.

There are, of course, countless consumer groups, from the Canadian Cancer Society through to the Canadian Organization for Rare Disorders. But they are not necessarily patient-driven, and funding research (which is laudable and appropriate) is often the focus.

But patients are more than a collection of body parts and diseases; someone needs to speak to the whole patient experience, and that is what the PAC is designed to do.

Patient-centred care has become the latest epiphany for health care administrators. There is now a broad recognition that the health care system has lost sight of who it was designed to serve – patients and, by extension, their family members.

The problem was well-articulated in a report prepared for the Saskatchewan

government entitled *For Patients' Sake*. The author, Tony Dagnone, said: "Our current health system has been designed around the people who deliver the care. It is time to realign the values of the health system so that the patient is again made the centre of attention."

But changing a culture, especially a well-entrenched one with many vested interests, is not easy.

For Dr. Glouberman, the starting point is understanding the root of the problem.

The health care system (or, more accurately, sickness-care system) we have today is based on a model that is more than a century old. It is designed to treat acute illnesses.

Patients who have suffered a severe trauma, who are dying of an infectious disease such as smallpox or who have just suffered life-threatening cardiac arrest, don't want or need input on their care. The need nurses and doctors who can save their lives, stat.

"The system is absolutely superb for that kind of acute care. It will save your life time and time again," Dr. Glouberman says.

But the vast majority of patients today do not need emergency care, they need chronic care and preventive care.

They don't need health professionals to save their lives in the instant, they need health policies (and sometimes health professionals) to empower them to live their lives for years and decades to come.

"Listening, hearing and caring is what patients want," Dr. Glouberman says. But those are largely antithetical concepts in our current sickness care system.

In Canada today, we have culture where the needs of the system almost

always take precedence over those of the individual patient. It's a culture that says that patients don't get choices, where dialogue is discouraged, where patient-provider relationships are fleeting, and where investing in customer service is not a priority.

It is profoundly undemocratic, shortsighted and costly.

We need an organized patient voice and some fundamental restructuring to help change that culture.

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