

“Patient participation in the healthcare system: from power relations to collaboration”

Report by: Marie-Eve Veilleux

On January 24, 2013, I had the pleasure to attend a Symposium hosted by University of Montreal’s Department of Health Administration entitled “Patient participation in the healthcare system: from power relations to collaboration”. Among the near 170 participants, I was surprised to learn that nearly 1/3 of the attendees were identified as patients. A good number of presenters were patients also.

The day started with an academic background of participant involvement and citizen engagement at different levels of the healthcare system both in Quebec and in France. Presenters gave a brief history of the medical ethics that prevailed before the 1950s-1960s where doctors played a paternalistic role in their patient’s care. They also spoke about the terminology used to refer to the reality of patient involvement in healthcare which was at the center of debates since the late 1990’s. In French, the term “consumer” was found to be too close to advocacy, while “client” referred to the private sector and “patient” was disqualified by the patients themselves. As it is in English, the terms you use will depend on who you are talking to. Four sectors of the healthcare system in which consumers play a role were identified: patients’ rights; satisfaction assessment; management of complaints and promotion of quality healthcare and services (including health care organization). A figure showed levels of patient engagements from low (complain, assess satisfaction, inform, train) and moderate (consult, advise, collaborate, and participate) to high (with the concept of co-construction).

The following presentation was from the Quebec Health and Wellness Commission (more info here: <http://www.cihr-irsc.gc.ca/e/45358.html#a6>). They have a consultation forum made up of 18 citizens and 9 experts in specific areas. They can make recommendations, but they don’t have any powers to decide. The presenter said it was “very good” that individuals on the panel didn’t have direct involvement in the issues discussed. I didn’t get a chance to ask why this was good in her opinion. I wonder why concerned patients aren’t involved – even in a smaller number.

A patient who is also a researcher presented on new concepts of patient participation in healthcare in France: therapeutic patient education; peers as essential part of health education; patient trainers; and patient researchers. Therapeutic patient education recognizes the capacity of the patient to learn. In 2009, a diploma was created in therapeutic patient education where 30% are patients and the counsellor is a patient researcher at the Faculty of Medicine. Several other initiatives were launched after as well such as “Patient universities”.

The next presenter was Shalom Glouberman of the Patients’ Association of Canada. This association is managed by patients to increase the role of patients and their family in Canada’s healthcare system. According to the presenter, in 2012, 89% of deaths in Canada were caused by chronic diseases. He made the parallel between the current system (built around acute care, hospital-centric where patients have little or no role in its design and changes) and the system that patients want (built around patients and their family, integrated management of chronic disease, focused on continuity of care, aimed at improving health as well as treating diseases). He stated that a system can’t be centered on patients if they don’t play a role in clinical care,

development of services, policy development and governance. He also mentioned some initiatives of the Patients' Association of Canada like the Patients' Choice Awards in collaboration with the Ontario Medical Association where physicians are rewarded for being committed to patient-centered care.

The next presenter was from University of Montreal. He talked about University of Montreal's Faculty office on the Patient*Partner Expertise. Among their different projects to focus on a new collaborative vision where "patients and health care professionals redefine their relationships to face the challenges of tomorrow", patients take part in three 1-credit courses to all medical students as patient trainers. The office aims at making patients full partners in teaching, research and health care. Here's a speech the director gave in English:

<http://www.med.umontreal.ca/doc/faculte/AMEE.pdf>

In the afternoon, we saw different patient participation initiatives presented by both patients and health care administrators that ranged from asking patients to help redesign an oncology waiting room, including children in the development of their treatment plan in a children's rehabilitation center, asking elderly to taste the recipes in a long-term care facility. In my opinion, that section was a bit disappointing because it confirmed that there is still a long wait to go until health administrators understand and apply the "co-construction" concept that was central to the morning's presentations.

The day ended with a presentation by an ethicist. She talked about the evolution of the patient/physician relationship from paternalism (500 BC to 1965) to autonomy (1945 to now) and bureaucracy (1990 to now). She also talked about four models of patient-physician relationship proposed by Robert M. Veatch (in his book "The Patient-Physician Relation: The Patient as Partner" parts of which are available in Google Books): the engineering model, the priestly model, the collegial model and the contractual model.

Finally, I had the opportunity to talk about patient involvement in research to a journalist from the Montreal Gazette who was very surprised and didn't see why we would want to be involved in research. I didn't hear back from her and didn't see anything about patient participation in the newspaper the following week. I also met with a young pediatric rheumatologist who is doing research about involving JIA patients in their care. She wants to adapt Patient Partners in Arthritis to children. I've been in contact with her and will be involved in her research.