The Patient-as-Partner Approach in Health Care: A Conceptual Framework for a Necessary Transition

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Abstract

The prevalence of chronic diseases today calls for new ways of working with patients to manage their care. Although patient-centered approaches have contributed to significant advances in care and to treatments that more fully respect patients’ preferences, values, and personal experiences, the reality is that health care professionals still hold a monopoly on the role of healer. Patients live with their conditions every day and are experts when it comes to their own experiences of illness; this expertise should be welcomed, valued, and fostered by other members of the care team. The patient-as-partner approach embodies the ideal of making the patient a bona fide member of the health care team, a true partner in his or her care. Since 2010, the University of Montreal, through the Direction of Collaboration and Patient Partnership, has embraced this approach. Patients are not only active members of their own health care team but also are involved in research and provide valuable training to health sciences students. Including patients as full partners in the health care team entails a significant shift in both the medical practice and medical education cultures. In this perspective, the authors describe this innovative approach to patient care, including the conceptual framework used in its development and the main achievements of patient partners in education, health care, and research.

Let the patient revolution begin.
—Tessa Richards et al

In recent decades, the epidemiological transition from infectious to chronic diseases has become a major public health challenge facing all countries, regardless of their economic status. Chronic noncommunicable diseases, such as heart disease, stroke, cancer, chronic respiratory diseases, and diabetes, are now by far the leading causes of death and disability in the world, accounting for two of every three deaths worldwide according to the Global Burden of Disease Study 2010. Our patient-as-partner (PP) approach appears both more relevant and better adapted to today’s challenges and the needs of most patients with chronic diseases.

Models in Transition

Over the past 20 years, paternalistic approaches to patient care have been losing ground. They have given way to patient-centered practices, in which health care professionals strive to reach a shared understanding with patients to respond more fully to their specific needs. Indeed, systematic reviews have shown that patient-centered care results in increased adherence to management protocols, reduced morbidity, and improved quality of life. Reducing the number of diagnostic tests ordered and referrals made has improved health statuses and efficiency of care. Although patient-centered approaches have undeniably contributed to significant advances in care and to treatments that more fully respect patients’ preferences, values, beliefs, and personal experiences, the reality is that health care professionals, especially doctors, still hold a monopoly on the role of healer. Meanwhile, we have witnessed the growing influence of alternative forms of medicine that foster less asymmetrical power relationships between caregivers and patients and a greater consideration of patients’ lived experiences and ways of knowing.

Initiatives, such as shared decision making, therapeutic education, expert patient, and self-management, have been inspired by patient-centered perspectives and offer innovative ways of involving patients in their own care. For instance, Tom Delbanco and colleagues’ work on inviting patients to read their doctors’ notes has been an important step in this direction. The PP approach is rooted in such initiatives yet takes a significant step forward into the realm of true partnership in care, where the patient is considered a caregiver of herself and, as such, a genuine member of the treatment team, endowed with competencies and limitations just like any other member of the team (see Figure 1). This approach aims to develop the patient’s competency in care instead of merely taking into account her personal experience.

The Patient’s Expertise

As the French philosopher Michel Foucault reminds us, “one must become the doctor of oneself.” At the heart of the PP approach is the notion of caring for oneself (epimeleia heautou), a concept that harkens back to the Socratic era—that is to say, to the birth of Western medicine in Greece. Indeed, as revealed by Plato, Socrates’s famous maxim “know thyself” is a call to heed one’s own needs. Foucault also argues that caring for oneself is, in fact, not simply...
a philosophical principle but an actual practice that, throughout the ages, has commonly prevailed: To some degree, every person has the ability to take care of himself. Patients are already taking care of themselves, sometimes in ways that health professionals are not trained to recognize (or are trained not to recognize), with varying levels of achievement depending on the normative framework chosen to determine success and failure.

Because self-care is a technique—that is, an activity based on a certain knowledge held by the individual—we must determine what knowledge a patient needs (or already has) to take care of herself. When dealing with incurable chronic diseases, experience becomes a well of critical information.

The key to successful doctor–patient partnerships is therefore to recognize that patients are experts too. The doctor is, or should be, well informed about diagnostic techniques, the causes of disease, prognosis, treatment options, and preventive strategies, but only the patient knows about his or her experience of illness, social circumstances, habits and behaviours, attitudes to risk, values, and preferences. Both types of knowledge are needed to manage illness successfully.

Seeing the patient as a caregiver does not mean involving him at every level of care; it does not mean including him in every meeting or consulting him on every decision. The doctor, nurse, physiotherapist, and other health care professionals each possess a certain expertise; similarly, so does the patient. None of the major interprofessional collaborative care models argue that all professionals on a care team must act together at all times and take part in all steps of the process. The PP approach does not argue this either.

Today’s much-hyped personalized medicine movement focuses mainly on genetics. However, it also could encompass a personalized approach to health care that incorporates patients’ particular preferences, experiences, and expertise and that would develop their individual competency in making care decisions. Indeed, if health care professionals were to fully consider these factors, many clinical dead ends might actually lead to breakthroughs, and many current challenges might be overcome. Scientific and experiential knowledge are complementary. Experiential knowledge may eventually be supported by science if a number of conditions are met (among them, the quality of the relationship, the patient’s self-confidence in her ability to mobilize her experiential knowledge during the medical encounter, the doctor’s recognition of the importance and the validity of this knowledge, etc.). The patient herself could initiate such a relationship, or she could do so in partnership with her health care professional.

**Changing Roles, Cultural Shifts**

Recognizing the existence and the validity of both scientific and experiential knowledge implies that sometimes the best decision for the patient is to not take the medicine prescribed. Such a proposition calls for a major shift in both the medical practice and medical education cultures:

Although there have been changes, and these are welcome, the powerful position of many doctors and the lack of appropriate training on how to work in partnership with patients still prevent the appropriate use of patients’ expertise and wisdom.

With the growth of chronic diseases, the role of the health care professional is no longer strictly one of healing; now it also includes accompaniment, solicitude, and guidance as patients undertake self-care. Health care professionals then must trust patients and acknowledge their successes in care, however minor they might be. The idea is for doctors to allow patients to actively take part in their own medical process, to recognize their ability to provide valuable feedback, and to entrust them with a certain degree of responsibility regarding quality and safety and the types of treatment decisions made by the health care team—of which they are a part—such that their involvement contributes positively to the entire process.

Today, universities and research funding agencies have been called on to respond...
to these changes. In the United States, the Patient-Centered Outcomes Research Institute, established by the 2010 Patient Protection and Affordable Care Act, has approved nearly 200 awards to date totaling more than $273.5 million to fund research guided by patients, caregivers, and the broader health care community. An example of such research is the pilot program “Zone of Openness” at the Palo Alto Medical Foundation Research Institute in California, which was designed to dispel patients’ fear of repercussions for asserting themselves in clinical decision-making processes and to help clinicians invite patients’ points of view. In medical education, the relationship-centered care initiative at Indiana University demonstrated that culture change is possible at a large medical school with a competency-based curriculum. At Yale University, the Department of Psychiatry has developed the Citizens Project, which provides peer mentor support services and nontraditional classes geared toward the rights, responsibilities, roles, and resources of community membership to adults currently in treatment for a psychiatric illness.

In addition, experiential knowledge is being shared between patients worldwide via healthtalkonline.org (formerly DIPEx from Oxford University), a Web site devoted to the sharing of patient experiences. Furthermore, over the past four years, patient universities have been created, most notably in Barcelona (Spain), Hanover (Germany), Paris (France), and soon Marseille (France), offering programs to develop patients’ knowledge in various areas. Expanding on this idea, in 2010, the University of Montreal (Canada) created the Office of Patient-As-Partner Expertise (now the Direction of Collaboration and Patient Partnership [DCPP]), co-led by a patient and a physician.

Our PP Initiatives

Rather than relegating patients to separate spaces (as in patient universities), the DCPP brings patients into already-existing structures to create true partnerships, thereby recognizing that they possess authentic, relevant, and valid understanding and expertise that can be immediately mobilized as a fruitful addition to the medical school curriculum. The recruitment of these patient partners is done mainly by patients themselves. We have developed a formal recruitment process and selection criteria, covering such elements as reflective capacity and ability to clearly express oneself (data to be published separately). Patients are truly the pivotal force in the DCPP. Health care professionals, students, academics, and teachers gravitate toward them in what has become an engaging and highly innovative knowledge production setting, completely integrated into our medical school.

More specifically, we have recruited and trained over 160 expert–patients who participate actively in health care, research, and training of health care professionals (see Box 1). Embracing the competency-based curriculum of our medical school, these patients are in the final stages of developing the first (to our knowledge) taxonomy of patient competencies (the work is led by coauthor Luigi Flora). This taxonomy will allow for the assessment and monitoring of patients’ development of skills and

Box 1

Components of the Direction of Collaboration and Patient Partnership (DCPP) at the University of Montreal, 2010

Education
- Seventy-five patient–trainers were recruited, trained—mainly by patients—and remunerated:
  - Patient–trainers provide training in interprofessional collaboration to all our health sciences students (13 health care and social services programs, for a total of approximately 1,200 students per cohort)
  - Patient–trainers cofacilitate (with health care professionals) interprofessional discussion workshops. They give feedback to students regarding the integration and application of the concept of partnership in health care from a patient’s point of view. The evaluation questionnaires completed by students are a testament to the perceived added value of involving patients in care processes.
- Sixteen patient–coaches accompanied new expert–patients in the education, research, or health care settings that were initiating or pursuing the patient-as-partner (PP) approach.
- A new mentorship program for medical students was developed (as a pilot project, with six patient–student dyads for the first year): a patient living with a chronic condition is a mentor for a medical student throughout his or her studies, rounds, career choices, sharing the good times and the challenges of the medical curriculum.

Health care
- Since 2011, the DCPP has accompanied 26 clinical teams, most of them hospital based (in primary care, oncology, and mental health, among other departments) in the greater Montreal area and the surrounding region, in the implementation of the care partnership–continuous improvement approach developed by Paule Lebel’s team.
- Professionals and patients are trained to work together and set joint goals, which makes this approach innovative.
  - It is not about patients being invited to join a professional committee to help meet predefined objectives but about a team truly co-constructing knowledge and decisions, in which everyone is trained to work together using the appropriate tools.
  - A first target is set jointly, then tasks are divided and, in action, the contribution of each individual is mobilized, recognized by the other members of the team, and accepted and valued.
- Preliminary results indicated a high level of satisfaction and a real change in the culture of health care settings toward a partnership that is no longer theoretical but actually embodied.
- Teams in primary care will start implementing the DCPP program; two of them did so in September 2014.

Research
- Extensive involvement with the Canadian Institutes of Health Research (CIHR), the chief federal agency responsible for funding health research in Canada
  - Counseling role for the development of the CIHR Citizen Engagement framework—the role of the framework is to better align funded research projects with patients’ needs (www.cihr-irsc.gc.ca/e/47275.html)
  - Membership on the Advisory Board of the Institute of Circulatory and Respiratory Health (www.cihr-irsc.gc.ca/e/45949.html)
  - Membership on the External Working Group on the “institutes model review”—the mandate of this working group is to review the structure, role, policies, budgetary framework, and slate of the institutes pertaining to their capacity to effectively respond to current and emerging health research challenges and to take advantage of national and international scientific opportunities to optimally deliver on CIHR’s mandate (www.cihr-irsc.gc.ca/e/47657.html).
The DCPP also plays an advisory role in the development of practice guidelines and policies that promote patient partnership for the Quebec Ministry of Health and Social Services. These guidelines include quality improvement, the fight against cancer, and primary care, among others. Finally, our patients advise executives and management teams in more than 30 health facilities in the province (over 350 directors and managers) regarding the establishment of a strategic plan, a governance structure, and work conditions that foster the development of partnerships with patients.

The Way Forward

We are not advocating for a new paradigm of disease or care that goes beyond all the precepts of patient-centered medicine but, instead, for the acknowledgment of the validity of patients’ experiences of illness and wellness. Patients, like professionals, have health care expertise. It’s high time we made use of it.

Certain areas of care (such as end-of-life care) and many health care professionals may already be practicing this type of medicine; we are not implying that everyone should start from scratch. Patients’ and health care professionals’ perspectives should be viewed as complementary—should not replace or supersede the other. The PP approach was based on the conceptual framework presented here and was designed by patients who were not in a dispute, angry at, or filing a claim against the health care system. Its development and implementation evolved (and still does) in situ—that is, we are finding evidence and building theory as we go along. Initial findings and the feedback we received so far from professionals, managers, patients, researchers, and students have been extremely encouraging.

Now that the PP approach is in its third year at our medical school and a number of Montreal hospitals and clinics, the next steps need to focus on important knowledge gaps regarding this relatively new way of approaching care in the context of today’s society. These steps will include:

- Assessing systematically the impact of the PP approach on:
  - patient and provider experiences
  - quality of care and patient safety
  - the acquisition of competencies by our medical and health sciences students

- Studying and understanding situations in which patients do not want a partnership role in their care and those in which it would not make sense to impose this role on them with the attendant responsibilities.

Another interesting track for future research would be to consider the impact, in terms of economics and the corporate presence in health care, of the changes in power in relationships that the PP approach implies.

The PP approach has its limitations and is certainly not a magic bullet to be used in all circumstances. However, it is our strong belief that such an approach will be key if we are to meet the greatest health challenges of our time—that of the increasing burden of chronic diseases worldwide and the critical need to redesign our health care systems accordingly—with any measure of success. This perspective is itself the product of a fruitful partnership between patients, health care professionals, and dedicated researchers. We have little doubt that it is the first of many for our team and others.

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Perspective


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