Patient Engagement: The Quebec Path*

COMMENTARY

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ABSTRACT

The issue on “The Patient Experience in Ontario 2020: What is Possible?” taught us how Ontario is trying to shift to a consistent culture of patient engagement at all levels of its healthcare system, from clinical to organizational and political. In this commentary, the authors share some of the avenues that have been taken in Quebec to structure patient engagement in a comprehensive way within and across stakeholder and patient populations. The model selected in Quebec is based on partnership of care and services, which includes not only patient involvement, but also interprofessional collaboration among professionals (Pomey et al. 2015b, 2015c).

The issue on “The Patient Experience in Ontario 2020: What is Possible?” taught us how Ontario is trying to shift to a consistent culture of patient engagement at all levels of their healthcare system, from clinical to organizational and political. We all know that our healthcare systems, built between 1940 and 1970, were structured around acute and highly specialized care provided by health facilities. Now, we see that needs have changed considerably over the last 30 years due to a significant increase in the prevalence of chronic diseases (Beaglehole et al. 2011), which is currently the leading cause of morbidity and mortality in Western countries (Jeon et al. 2009). In particular, in Canada, 65% of the population aged 12 and above and 90% of  

*This article is a response to “The Patient Experience in Ontario 2020: What is Possible?” Healthcare Papers 14(4): 8–18. doi:10.12927/hcpap.2015.24339
people aged 65 and above report having at least one chronic disease (Statistics Canada 2013). This trend will worsen in the coming years in all countries of the Organisation for Economic Co-operation and Development (OECD) (2013). Given this context, many countries have been rethinking how to better integrate patient participation within the various levels of governance of the system, whether at the clinical, organizational or strategic levels (Richard and Lussier 2010). Quebec is no exception in this respect; in fact, we are trying to lead this new quiet revolution, which will help us answer the challenges our healthcare and social services system is facing. In this commentary, we would like to share some of the avenues that have been taken in Quebec to structure patient engagement in a comprehensive way within and across stakeholder and patient populations. The model selected in Quebec is based on partnership of care and services, which includes not only patient involvement, but also interprofessional collaboration among professionals (Pomey et al. 2015b, 2015c).

**Fundamentals of Patient and Professional Partnership**

The Patient and Professional Partnership perspective proposes that the patient be considered as a healthcare provider, an equally valued member and partner of the healthcare team (Karazivan et al. 2015). Over 20 years, paternalistic healthcare approaches have gradually given way to patient-oriented approaches that take into account patients’ differences, values and experiences (Stewart et al. 1995). When patients are dealing with a chronic disease that generally cannot be fully cured, its evolution is closely tied to their lifestyle. As patients have to live with the illness for the rest of their lives, their experience becomes a rich source of knowledge, essential for decision-making (Jouet et al. 2010, 2012). The Patient and Professional Partnership perspective (Figure 1) defines patients’ experiential knowledge as “the knowledge a patient develops from the experience of health and psychosocial problems, from the trajectory of care and services and the impact of these problems on his personal life and that of his relatives” (Comité sur les pratiques collaboratives et la formation interprofessionnelle 2013a), and recognizes the importance of this experience for decision-making at the clinical, organizational and strategic level.

Thus, from the perspective of partnership, decision-making and quality care actions are based on the scientific knowledge of professionals and on the experiential knowledge of patients living with the disease (Comité sur les pratiques collaboratives et la formation interprofessionnelle 2013a). Moreover, patients must be able to assert their experience and their experiential knowledge, to take part or even to exert some leadership in making decisions concerning their own case, just as professionals bring their clinical expertise (Comité sur les pratiques collaboratives et la formation interprofessionnelle 2013b). A patient’s ability to interact with professionals depends both on the level of their illness experience (experiential knowledge acquired progressively through living with the disease) and on the degree of development of their interpersonal communication skills (ability to communicate their knowledge to the team) (Comité sur les pratiques collaboratives et la formation interprofessionnelle 2013b).

Collaboration between patients and healthcare providers also assumes that the professionals will take responsibility not only for keeping patients informed, but also for maintaining a learning relationship with them. This is to ensure they develop an understanding of the disease, its determinants and its treatment, so they can gradually become independent and active in the dynamics of care (Coulter and Ellins 2007). Fully understanding this interdependent relationship makes it possible to re-evaluate the approach for treating chronic diseases.
Patient and Professional Partnership is part of a continuum of patient involvement (Carman et al. 2013; Pomey et al. 2015c) that begins with information sharing and culminates in partnership. Sharing information via documents, websites and testimonies gives patients access to knowledge that may be relevant to them. At the consultation stage, patients are given the opportunity to express their point of view on given situations. At the collaboration stage, patients participate in decision-making. And finally, at the partnership stage, patients are equipped to take their place on equal footing with the professional practitioners to ensure the most effective intervention. This involvement can take place at the micro level, i.e., as part of an individual pathway of care and services; at the meso level, as part of the framework for organized care and services and for governance of establishments; or at the macro level, in the development of programs or policies on a population scale, or in the organization or governance of the system (see Table 1).

As this philosophy has made its way through the healthcare system, it has led to several projects that have been deployed at the strategic, organizational and clinical levels.

**Examples of Patient and Professional Partnership Implementation**

**At the strategic level: Bill 10 and partnership**

In February 2015, the minister of health and social services (MSSS) had the Quebec Parliament enact Bill 10, which provided for a complete restructuring of Quebec’s health and social services network. The basic principles of the reform were: (1) merging health and social services establishments at the regional level to achieve integration and continuity of services; (2) regional population responsibility taking into account social determinants of health and needs in the area of health and services; (3) central decision-making to reduce discrepancies in how care and services are provided.

In this context, the MSSS created 9 Centres Intégré Universitaire de Santé et de Services Sociaux (CIUSSS – Integrated Health and Social Services University Centres) and 13 centres without university affiliation (CISSS), and promulgated a strategic plan for all of these organizations, with a core priority that systems be in partnership with patients and adapted to their needs (Ministère de la santé et des services sociaux). This then translated into the organizational charts that were presented to CISSS and CIUSSS, in which partnership of care is included at the clinical level,
and deployment of partnership of care and services is included by the departments for evaluation, quality, ethics and performance. Additionally, the ethics and quality department of the MSSS undertook consultations with patients, practitioners and experts to draft professional policies on how to implement partnership with establishments. This co-construction was the first of its kind to be realized in Quebec.

At the organizational level

**The partnership of care program**

Some establishments have joined the Partnership of Care Program (PCP) offered by the Collaboration and Patient Partnership Unit (CPPU) of the faculty of medicine of the University of Montreal, which helps care teams take on patients in order to improve care and services. After raising management’s awareness of the importance of partnership between patients and professionals, a voluntary program assesses the teams’ ability to develop interprofessional collaboration interdisciplinarily. Based on this assessment, continuous improvement committees (CIC) of 8–10 people are set up, including at least two patients or family caregivers, two or three professionals, one doctor and one clinical manager. The patients on these committees are individuals who have received care within the program, but are no longer in acute treatment and are willing to contribute their experience to improve services. They are trained and coached by more experienced patients from the CPPU. The professionals participating in CICs are also trained on partnership, and all members of the CIC are supported by a leader in collaborative practices for the establishment, to help them through the process. In this way, the CICs conduct continuous quality improvement cycles. Each cycle lasts a maximum of six months. The first evaluation of this program, conducted by 26 teams across Quebec (Direction Collaboration et Partenariat Patient 2014), helps improve care and services and integrates the partnership of care and services approach within establishments.

From the perspective of management, the process has served to introduce a change in culture that favours collaboration between managers, doctors and patients. For teams, it has (1) given more meaning to their activities and a better idea of the impact they have on patients and their families during daily interactions, and (2) strengthened teamwork by making it necessary for practitioners to consult each other and orient their actions according to the

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Table 1. Continuum of patients’ engagement (adapted from Pomey et al. 2015b)

<table>
<thead>
<tr>
<th>Participation level</th>
<th>Information</th>
<th>Consultation</th>
<th>Implication</th>
<th>Partnership co-construction</th>
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<tr>
<td><strong>Direct care</strong> (micro = clinical)</td>
<td><strong>Patients receive information (diagnosis, treatment)</strong></td>
<td><strong>Patients are consulted on their perceptions</strong></td>
<td><strong>Shared decision about therapeutical preferences</strong></td>
<td><strong>Patients make their own decisions based on their life objectives; interdisciplinary intervention plan</strong></td>
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<td><strong>Organization and quality of services</strong> (meso = organizational)</td>
<td><strong>Documentation given to patients on their illness</strong></td>
<td><strong>Focus groups on specific themes</strong></td>
<td><strong>Creation of committees with patients</strong></td>
<td><strong>Co-construction of services, programs, quality improvement projects</strong></td>
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<tr>
<td><strong>Health policies</strong> (macro = political)</td>
<td><strong>Information centre for patients and/or for the media</strong></td>
<td><strong>Focus groups to collect public opinion</strong></td>
<td><strong>Recommendations made by patients on healthcare priorities</strong></td>
<td><strong>Co-construction of health policies with patients/citizens</strong></td>
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Factors that influence patient commitment

Belief, literacy, education, organization, culture, practices, society, standards, regulations and policies
patient’s life plan. Finally, for patients, their involvement (1) provides an opportunity, while feeling welcomed and respected by practitioners, to ensure their experience benefits other patients; and (2) gives meaning, in a constructive and rewarding way, to the experience of their past utilization of health services (Pomey et al. 2015d). Despite some difficulties in matching practitioner and patient schedules, initial studies on the impact of the partnership of care and services show an improvement in the technical and relational quality of care (Direction Collaboration et Partenariat Patient 2014).

Structuring patient involvement at all levels of a healthcare establishment
Another experiment conducted at a CIUSSS and funded by the Canadian Foundation for Healthcare Improvement (CFHI) helped structure patient involvement at all levels of governance of the establishment (Pomey et al. 2016). To this end, the organization recruited a patient advisor two days a week, along with a manager, to develop a reference framework for patient involvement at the strategic, tactical and operational levels, as well as tools such as a form to request patient advisor participation and learning material. This made it possible to select, train and coach patient advisors to participate in different activities during the 18 months the strategy was implemented: providing their opinion on educational material given to patients; reviewing the establishment’s code of ethics and partnership evaluation tools; sharing their testimony with professionals and managers; participating in continuous quality improvement or Kaizen groups; being involved in training residents/interns (doctors, nurses, social workers, psychologists, pharmacists, etc.). This experience of patient involvement was greatly appreciated by both the managers and the patient advisors. It brought them back to the fundamental meaning of the patient–practitioner relationship and helped incorporate the patients’ experiential knowledge into improvements in care and services.

At the clinical level
A promising avenue: Patient advisors at the bedside
One promising avenue for partnership of care and services is introducing patient advisors at the clinical level. These patient advisors are patients themselves who have been through care episodes and are ready to share their experiential knowledge with other patients facing a similar episode. Thus, at the Centre hospitalier de l’Université de Montréal, patient advisors are gradually being introduced in different areas. One project funded by CFHI involved introducing patient advisors at the Centre d’expertise en réimplantation et revascularisation de la main (Centre for Hand Reimplantation and Revascularization). Patients who have undergone an amputation or revascularization of the hand help new patients, who have recently been the victims of an accident, to get through the 12 months of post-surgery rehabilitation. The first assessments of the impact of this involvement show improvements in adhesion to treatment, recovery of functionality in the hand, psychological health and social reinsertion (Vigneault et al. 2015; Pomey et al. 2015e).

In conclusion, Quebec has officially adopted Patient and Professional Partnership in its strategic plan, and structuring initiatives have begun in recent years and are being consolidated, possibly to be deployed across all health and social services establishments in the province. It would be interesting in a few years to assess the impact of the Bill 10 reform on the deployment of Patient and Professional Partnership (Pomey et al. 2015a). Comparisons with other provinces, such as Ontario, will help us develop the best practices that we need to understand how patient engagement can help improve the quality, security and performance of our health and social services system.


