

Patient-Centred Care: The Proving Ground for Continuity and Equity in Our Health System

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IN CONTRAST TO usual practice in *Healthcare Papers*, we will start this editorial with a personal story. Several years ago, one of our parents (ADB's mother) was diagnosed with her fourth cancer, at a late stage and with little question about the eventual outcome. Her son was still at a relatively early stage in his career and at an even earlier stage in his personal life, having just gotten married. So she decided that she would play for time. She talked with her physicians and surgeons about her preference for quantity of time over quality of life, and they agreed on an aggressive course of treatment. However unpleasant the side effects of treatment were, she would have rated her experience as overwhelmingly positive because her goals drove treatment decisions.

After a short while, the physician responsible for her care moved to another job and her new physician recommended palliative care and did not recommend further treatment. We cannot comment on the clinical reasoning behind this decision, but we can share how the story ended. She switched physicians, completed several more unpleasant rounds of chemotherapy and got to see several milestones, including – for her most importantly – the birth of her two grandchildren. Several years later, she did enter palliative care, where again her goals drove treatment plans and she was able to die at home as she wished.

In this one, highly personal case, we can see three examples of strong patient engagement with a good patient experience and one

case where poor patient engagement could have derailed a patient's goals across the entire trajectory of care. We can also see the ability of patients and their caregivers to navigate the system and to make sure it responds to their goals. But, like many of the readers of this Journal, we come from highly educated families with strong connections into the health-care system. Would the story have ended as well as it did if we lacked the good fortune of our educations and connections?

In their lead essay, Fooks and colleagues (2014) lay out an ambitious vision for building patient-centred care across the Ontario health system. Their thoughtful categorizations and definitions and the elements they lay out for transformation are simple and rational (although they may not be easy to implement). Highlighting the challenges of implementing this vision, they note that "There was lots of enthusiasm about the why but some skepticism about the how" (p. 14).

We would like to add three additional but necessary challenges to implementing (the how of) the vision. In the lead paper, the importance of integration of care is implicit: transitions of care should be seamless with clear understanding of treatment plans and goals across sectors, all information should be available electronically and so on. Without this integration, the weakest link in patient-centredness can damage patient experience across the entire trajectory of care.

The second is to recognize that shifting to a consistent culture of patient engagement within and across providers and institutions represents a profound change in practice for many individuals and organizations. Effective patient engagement is a skill set and a mind set that should be core elements of all health professions' curricula. It should also be a key element that permeates continuing professional development programs to assist those already in practice and not just the

next generation of providers. Again, the consistency of the culture around patient-centredness is critical to maintain a positive patient experience.

The third, and related, idea is that education about patient engagement should extend well beyond providers. There is a growing acknowledgement about the need for health literacy among patients and even the general public. An increasing number of hospitals are creating patient education centres; videos by health professionals such as Dr. Mike Evan's YouTube channel are creating "virtual knowledge centres" for patients; and web sites like patientslikeme.com are peer-to-peer educational venues designed to increase patient knowledge about their illnesses and care. In and of themselves, these efforts to improve health literacy will help with patient engagement, but we believe there should be an explicit effort to make patients aware of the importance of their engagement in their care and provide them tools to support their own engagement.

Finally, we also want to emphasize the importance of equity in these considerations. The story we shared ends positively but perhaps as much because of the privileges one family had as because of how our system works. When we think of patient-centredness, our tools must be robust enough that they can engage all patients. Only this way will we make sure that efforts towards greater engagement do not further favour only those who have a voice within our system. Simply put, patient engagement should improve the experience for all, not perpetuate privilege. Equity, a key domain of quality, is not yet measured and managed as a goal within the Ontario health system, nor within many others. We will need to make sure that it becomes such across Canada, so that we can see the impact of patient engagement across all communities of patients.

The lead paper and the commentaries included in this issue all re-enforce the criticality of patient engagement to the performance of our health system. Many of the commentaries provide tools such as new indicators or stories and perspectives such as that of clinicians to help achieve a truly patient-engaged health system. While skepticism about the how will persist – and may even be accentuated by the two (three?) additional challenges we present in this editorial – we must begin the hard work of implementation across our health systems for everyone in these systems.

Reference

Fooks, C. , G. Obarski, L. Hale and S. Hylmar. 2015 “The Patient Experience in Ontario 2020: What Is Possible?” *Healthcare Papers* 14(4): 8–18, doi:10.12927/hcpap.2015.24339.