

Patient Engagement: We Need to Get on With It



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ABSTRACT

We are extremely grateful to each of the commentators for their thoughtful responses to “The Patient Experience in Ontario 2020: What is Possible?” It was helpful to hear the perspective and insights of authors from different jurisdictions and to benefit from their knowledge and experience. There are a number of themes that emerged from the commentaries that we would like to highlight.

Language and Terminology Are Important.

All of the commentators agreed that language and terminology are important, with different positions on preferred concepts. Cornwell (2015) referred to The Point of Care Foundation’s research on terms like “relationship-centred,” “personalized” or “individualized” care, and “patient and family-centred care.” Two findings from that research were of particular interest – health professions do not share a common language for a good experience of care, and the significance of words can change over time. Green and Moody’s (2015) advocacy for “person-centred care” as a more inclusive term might help move the conversation forward.

Both Cornwell (2015) and Simpson (2015) argued that the relational aspects of patient-centred care, patient engagement and

patient experience are foundational. Simpson referred to the term “household-centred care” as representative of a relational care goal, but noted that even this term was problematic as it lacks the provider perspective. Cornwell’s categories of transactional and relational dimensions of care – i.e., the “what” of administrative and clinical transactions, and the “how” of relations – enhances our thinking on patient-centred care, patient and family engagement, and the experience of care.

The concept of “experts” was another term that garnered discussion. Thompson (2015) referred to “lived-experience experts” and to increasingly referenced data comparing the time in a year that people with chronic conditions spend with professionals (miniscule) and the time spent self-managing. Balik (2015) referred to the “knowledge and wisdom” that each party – patient and families and

healthcare professionals – brings to the partnership. We first heard the term “experts by experience” from National Voices, a coalition of charities in England that works for a strong patient and citizen voice in health and social care, and now “experts by experience” are a key partner of the National Health Service (NHS) England Care Quality Commission in achieving its quality mandate. It is clear that “value is created when people with different and complementary areas of expertise are working together for a shared purpose” (Thompson 2015; p. 38).

The discussion and debate around language and terminology is useful – it means people are thinking about the meaning of words, what they convey and what they are trying to achieve. The process of coming to agreement on terms and language, in and of itself, can help to build partnerships and mobilize progress towards improved experiences of care.

How Fast Can or Should We Move on This?

The commentators had different views on preferred timelines, with Thompson (2015) and Balik (2015) suggesting that we are not going far enough or fast enough to achieve patient-centred care, and Simpson (2015) arguing that we may be going too far, too fast, given the importance of including the provider and system perspectives in achieving patient centred care. Cornwell (2015) is right in noting that regardless of speed the journey to truly patient centred care will require cultural change.

Balik (2015) provided specific examples where implementation could be quicker. One suggestion was faster implementation of patient and family charters as long as they are developed with patients and family, along with providers. Green and Moody (2015), and Balik advocated for charters that are

“living documents” that are “regularly used to improve systems of care” rather than a document that is merely posted in an organization’s lobby. This encourages a view of patient and family charters as aspirational documents which describe what people within an organization – patients, family caregivers, providers, staff, volunteers, leaders - aspire to in terms of a philosophy of care, and not a checklist of rights and expectations that requires a remedy process should rights not be met.

The inclusion of the provider perspective and attention to the relationship between staff experience and patient experience was advocated for by Simpson (2015) and Cornwell (2015). The experience of the Northumberland Ontario PATH project (Partners Advancing Transitions in Healthcare) was that early on the pendulum of energy, resources and “privileging” of voice swung noticeably to the patient and family caregiver side. Although providers were part of the co-design process, the driving force was patient and caregiver views. Simpson referred to “this privileging of patient and family perspectives as an important corrective to a traditionally ‘provider-centric’ system.”

To bring about change, it will be imperative to work in partnership with provider groups and associations. Thompson reflected on Kingston General Hospital’s journey – “we put a stake in the ground by declaring that any decision in our organization where there is a material impact on the experience of patients, a patient will be at the table” (2015; p. 34) And she has challenged others to do the same.

There Will Be Challenges and Barriers

The commentators discussed various challenges and barriers associated with achieving patient-centred care and meaningful patient engagement for improved patient experiences. Balik (2015) and Thompson (2015) pointed out that a key barrier to change is the

perception of many providers that they are already patient-centred and they engage patients and families effectively. The key will be to motivate providers to critically challenge this perception.

The communication challenge was commented on by all authors. Simpson captured the essence of the challenge – “communication, verbal and non-verbal, is the vehicle of every care interaction, the bedrock of each therapeutic relationship, and a major influence on underlying trust” (2015; p. 34). New competencies in communication between patients, family caregivers and providers will be required to support a shift to new partnerships in care.

A number of commentators also spoke about the barriers to meaningful engagement. Cornwell’s question is intriguing – “What is it about patients’ experience that makes it different from the other dimensions of quality (i.e., patient safety, clinical quality) and sets the barriers to patient engagement so high?” (2015; p. 23). She points out that “for health professionals, the thought of engaging with patients about their own experience of care raises deep anxiety” (2015; p. 23). Future success will depend upon conversations unfolding between providers and patients in such a way that providers can see the benefits.

Patient and Family Advisory Councils (PFACs) were discussed by a number of commentators. Interestingly, the U.K. does not have PFACs, and Cornwell writes “it seems possible that Ontario is ahead of the U.K. on patient engagement generally.” Certainly the leadership role of Cancer Care Ontario – and Green and Moody (2015) – has advanced the PFAC model in regional cancer centres and the provincial renal network in Ontario.

Social media was identified by a number of commentators as an influential and equalizing force that is responding to some of the barriers to change. Thomson viewed social

media as “a democratizing force that is changing the way people access and use knowledge” (2015; p. 39). Cornwell referred to a number of patient leaders in the U.K. who, “partly through their use of social media, have national profiles and influence on policy” (2015; p. 23). It is not a coincidence that the proliferation of social media coincides with the rise in patient engagement and the push from patients and families to be formally recognized as part of the care team. The Ontario health system will need to pay attention to this.

Establishing Metrics and Building Evidence Is Important

The commentators spoke of the importance of metrics and an evidence base for patient-centred care and patient engagement. Cornwell wondered whether physicians were not getting involved more readily because “the evidence for patient experience comes from sources – patient surveys, complaints data, qualitative research – that do not easily fit into the scientific paradigm of evidence-based medicine?” (2015; p. 24). Simpson argued that “to be taken seriously in the evidence-based milieu of healthcare, any proposal related to system revision needs hard numbers to back it up” (2015; p. 32).

Quantitative data is one piece of the evidence base. And the PATH project has demonstrated that qualitative data – and specifically storytelling – is an equally important piece and can be a powerful motivator for change. Cuthbertson’s (2015) description of B.C.’s patient-centred measurement program underscores the importance of both quantitative survey results along with qualitative patient stories. Furthermore, Cuthbertson’s description of B.C.’s Patient-Centred Measurement Plan is moving the measurement yardstick forward by asking people who receive healthcare services for their feedback across their entire episode of care.

Glouberman's (2015) description of the work of Patients Canada also underscores the importance of ensuring that patients and family caregivers – and their experience of care – is integral to research design and the development of targets for change.

Conclusion

The horse is out of the barn. People are feeling empowered – un-empowering them is not an option. We need to get on with it – to benefit from that expertise, to harness that energy – to improve the patient experience.

References

Balik, B. 2015. "A Challenge to Aim Higher and Bolder." *Healthcare Papers* 14(4): 41–5, doi:10.12927/hcpap.2015.24344.

Cornwell, J. 2015. "Language that Works for Everyone." *Healthcare Papers* 14(4): 19–25, doi:10.12927/hcpap.2015.24340.

Cuthbertson, L. 2015. "Patient-Centred Measurement in British Columbia: Statistics without the Tears Wiped Off." *Healthcare Papers* 14(4): 46–56, doi:10.12927/hcpap.2015.24345.

Glouberman, S. 2015. "Partnerships with Patients and Family Caregivers." *Healthcare Papers* 14(4): 57–63, doi:10.12927/hcpap.2015.24346.

Green, E. And L. Moody. 2015. "Winning Conditions?" *Healthcare Papers* 14(4): 26–30, doi:10.12927/hcpap.2015.24341.

Simpson, C. 2015. "Finding Common Ground in Patient-Centred Care: Consensus, Communication and Conversations for Change." *Healthcare Papers* 14(4): 31–7, doi:10.12927/hcpap.2015.24342.

Thompson, L. 2015. "Patient Engagement: Time to Shake the Foundations." *Healthcare Papers* 14(4): 37–40, doi:10.12927/hcpap.2015.24343.

