

# Experience of Care – Furthering the Patient Experience Agenda



COMMENTARY

*Jennifer Quaglietta*, BAsC, MBA, CHE, PMP, LSSGB  
Director, Patient Experience, Quality, & Patient- and Family-Centred Care  
North York General Hospital  
Toronto, ON

*Karyn Popovich*, RN, BHS, MHS, CHE  
Vice President, Clinical Programs, Quality & Risk, & Chief Nursing Executive  
North York General Hospital  
Toronto, ON



## ABSTRACT

*The measurement of the patient experience is a global movement that has caught the attention of healthcare reformers. The use of patient experience data to ameliorate healthcare practice is promising, although standardization in what, where, how and whose experience is measured does not yet exist. To truly further the patient experience agenda, there needs to be adoption at the system, regional and local level to help promote, inspire and lead to sustainable change. Caregiver insight into the patient experience should be leveraged to learn what is important to patients and extract more useful data, as they are often present during transitions in care that span across the continuum. Embracing the voice of the patient as part of the process to improve quality, outcomes and experience will no doubt lead to impactful change and better care.*

### **The Patient Experience**

Patient- and family-centred care and the patient experience are critical aspects of care

quality. Positive patient care experiences are associated with higher levels of adherence to recommended prevention and treatment

plans, better clinical outcomes, improved patient safety within hospitals and less health-care utilization (Anhang Price et al. 2014). Collecting patient and caregiver experience information will no doubt have a positive impact on the patient-centred improvement of health system delivery in the future. Currently, the lack of standardized instruments to collect and benchmark data may be limiting the success of organizations to improve care. In the short-term, intentional rounding to carry out patient interviews may suffice. However, in the longer term, rounding coupled with the use of real-time and longitudinal surveys would be even more beneficial as improvements and modifications can be made in a timely way rather than long after the patient has left the system and trends can continue to be leveraged. In Canada, healthcare organizations have placed an increased emphasis on providing patient- and family-centred care to better respond to the needs of patients and to improve the quality of care (CIHI 2017a). In 2010, the Ontario Ministry of Health and Long-Term Care (MOHLTC) passed a seminal piece of legislation, the Excellent Care for All Act (ECFAA). ECFAA formalized the shift in the healthcare system from provider-centric, to one that is patient-centred, embodying the government's commitment to provide quality care that is focused on patients and driven by improving outcomes and satisfaction (MOHLTC 2010). Furthermore, the MOHLTC has made improving the healthcare experience the cornerstone of its *Patients First* action plan (MOHLTC 2015). Strategically, at the provincial level, organizations such as the Canadian Institute for Health Information (CIHI) and Health Quality Ontario (HQO 2017) are collecting and reporting on information collected from the National Research Council Health (NRCH) longitudinal surveys to drive system change. NRCH data are used in combination

with collected comments to drive specific and targeted improvements in particular areas where trends are noted and focused attention will improve the overall experience of care. An example of this can be noted in the annual Quality Improvement Plans (QIP) that hospitals are required to submit to HQO. HQO has prioritized the patient-centred indicators to be collected, and shares projects/tactics that have made improvements via their QIP Navigator Tool. In this example, HQO is supporting focused system improvement in a particular area, and helping to spread and scale ideas for change. Tactically, at the provider and organization level, the data support open dialogue at the clinical level where interdisciplinary teams, joined by Patient and Family Advisors/Partners, collaborate and work to see direct improvements at the bedside.

In the lead article (Kuluski et al. 2017), the authors' recommendations highlight critical components of measuring the patient experience that will help drive the patient experience agenda forward. These recommendations need to be further expanded, explored and addressed to ultimately accelerate the measurement, analysis, improvement and reporting of the patient experience.

### **Elements of the Care Experience that should be Measured**

It is common for patients to access and receive various types of care across the healthcare system, in different organizations and locations. Given that each healthcare organization has a unique culture, vision, mission and healthcare delivery philosophy, the patients' care experience will vary. Thus, it may be difficult to select only a few elements of care to measure. To fully propel system change forward, a deeper understanding of how to measure the patient experience from patients, family members and caregivers is also required. Patient perspectives and insights

of what patient experience means to them will vary based on individual values, beliefs, cultural backgrounds and more. To provide actionable insights, we can start by asking the right questions, in the right language, at the right time with considerations for how to drive change forward with the data. Although it may appear complex, collecting patient satisfaction data can be simpler than expected. If there was a way to find more time at the bedside, asking patients, family members and caregivers their input and feedback in the moment, the notion of multiple sources to collect data, in different languages, at the right time, in the right place, by the right person becomes more manageable. To get to the deeper understanding, the manner in which elements are collected comes into question. In terms of collecting information, variation still exists in the types of surveys administered (standard questions and definitions of those questions), how we collect data and where we store it. There needs to be focused, clear lines of accountability and transparency, with data that are applicable, relevant and relatable so that it can help promote, inspire and lead to system, regional and local level change.

In their article, Kuluski et al. propose a number of noteworthy elements of the care experience that should be explored and considered to improve the quality of data collected. For example, health literacy, previous experiences and a qualitative summary of the personal experience, likely play an important role in the overall patient experience, as they provide valuable insights in developing action plans for change going forward. Although qualitative data collected through the use of open-ended questions will no doubt provide significant value, it could require tremendous amounts of resources which are scarce in our current healthcare system.

One indirect method to capture this qualitative narrative is through the use of

“story-telling.” Sharing the patient story is a cost-effective and powerful tool used to create intentional dialogue about the patient narrative to drive conversations beyond the ailment. Stories bring the “human impact” into play, allowing for empathy, reflection and honest opportunities for change. Although a more proactive collection of data through open-ended questions would certainly yield valuable information, in a resource-limited environment, “story-telling” could be a useful avenue to pursue. The sharing of experiences and stories can easily be integrated during daily huddles or unit specific rounding. As Dr. Donald Berwick states, “Measurement is crucial – but if we forget the stories it will mislead us” (Berwick 2002).

*Caregivers offer a more comprehensive picture of reality and often can shed light ... into the needs and desires of the patient ...*

### **Experiences that we should Measure**

Surveys of patient experiences directly evaluate the degree to which care is patient-centred and thus capture an intrinsically important dimension of quality of care, regardless of the correlation between patient experience and other indicators of healthcare quality (Anhang Price et al. 2014). The experience of the primary caregiver is already an active area of engagement in developing the overall patient experience agenda. Caregivers offer a more comprehensive picture of reality and often can shed light or provide key insights into the needs and desires of the patient, and in several situations can act as the only form of reliable feedback with respect to the patient’s experience. While the information is valuable, considerations for language barriers, age and chronic conditions are examples of just a few obstacles that can reduce the quality of data collected.

Kuluski et al.'s recommendation on capturing and measuring the caregiver experience as it relates to the patient experience should be a recommendation considered for adoption across all healthcare settings. Seventy per cent of care is provided by unpaid caregivers (Ontario Caregiver Coalition 2017). Thus, it makes sense that the primary caregiver experience should be integrated into the overall measurements of the patient experience. Caregiver feedback can easily be integrated into the patient experience via two pathways: real-time surveys and/or through modifications of longitudinal surveys collected post care. Ensuring that the caregiver is an included and active participant of the healthcare team may be an additional component of caregiver experiences that need to be monitored. Kuluski et al.'s suggestion on expanding our health policy to include aspects of the UK's *Carers Act* would fundamentally change the adoption and practice of incorporating caregivers into the patient experience process, and ultimately push the patient experience agenda forward.

There is one other experience that should be considered: that of the healthcare workforce (healthcare providers, physicians, administrators and staff). A recent study has reported widespread burnout and dissatisfaction among members of the healthcare workforce (Bodenheimer and Sinsky 2014). Although Dr. Berwick brought forward "The Triple Aim" proving that improving patient satisfaction leads to increased health outcomes and decreased costs, burnout has been correlated to imperil it (Berwick et al. 2008; Bodenheimer and Sinsky 2014). To have patients, families and caregivers partnering together in a meaningful way with the workforce may provide better engagement and greater joy in practice (Frampton et al. 2017). All providers in their individual workplace settings, should be surveyed on their joy at work and workplace engagement. Braithwaite

and colleagues (2016) are currently conducting a review that will identify how and the extent to which, organizational and workplace culture impacts the effect on patient outcomes – the results, when available, will be telling. Surveying workforce engagement on a regular basis, and combining the analysis with the overall patient experience data, will provide a more fulsome data set of the factors influencing the patient experience.

### **Right Time, Right Place for Measuring**

Our healthcare system presents barriers to capture the true, lived patient experience, especially for those with complex conditions requiring multiple transition points and varying types of intervention. Healthcare received across the continuum should be seamless, integrated, electronically accessible and well understood (Brown and Tepper 2015). There have been a number of survey tools developed for the acute care sector to measure patient satisfaction; however, under-utilization of those tools remains a significant issue. Efforts by the Ontario Hospital Association to support the acute care sector in survey tool uptake have been instrumental in driving adoption; however, the absence of a cross-sectoral tool that measures the patient experience continues to be a challenge (Ontario Hospital Association. 2014; CIHI 2017b). Furthermore, HQO has mandated hospitals to select patient experience as a priority indicator for QIP. Given both organizations' focused efforts to gain adoption for measurement, there still remains a need to push the patient experience agenda forward – within the acute care setting. The Local Health Integration Networks may be able to support this discussion, bringing together various key stakeholders across the system, and to promote a culture of continuous improvement. Working in a system where "silos of care" (acute, primary and community) still prevail results in a lack

of overall accountability for care along the patients' journey. A model currently being studied at North York General Hospital and evaluated by the University of Toronto, brings together acute, primary and home and community care services into one coordinated pathway for condition-specific patients. This pathway was developed in partnership with and input from our patients, families and caregivers. Integrated care pathways allow for the patient experience to be measured across the continuum at all transition points. Early findings are promising, suggesting that this type of integrated care model – when organizations come together and are funded to manage the needs of patients throughout their journey of care – allows for measuring, monitoring, improving and reporting on the patient experience to become achievable.

### **Moving Forward**

Patient engagement is the way in which patient needs and preferences are solicited to ensure that healthcare providers and organizations are delivering patient-centred care (Fooks 2015). Inviting the patient and family voice into an organization (e.g., Patient and Family Advisory Councils [PFACs]) serves as a pillar in the creation of an engagement-capable environment. Across the country, roles for PFACs have been further expanded and mandated. In addition, Accreditation Canada recently increased their focus on acute care organization standards and has integrated specific requirements regarding activities that take place with feedback from patients and families (Accreditation Canada 2014).

The voice of the patient, family and caregiver through their collected experiences creates a resource for the recommendations and feedback that will ultimately lead to impactful solutions and an opportunity for change. Successful implementation of PFACs does not require many resources, but does rely on a shift

in organizational culture. Unfortunately, lack of support in Ontario remains a barrier, as not all hospitals have PFACs in place (The Change Foundation 2014).

Kuluski et al.'s recommendation to embed measurement within more engagement-capable environments is a critical component to the overall success of moving the patient experience agenda forward. Although Kuluski et al. present a range of noteworthy pilot projects, prior to implementing any one of these, it would be prudent to await the release of HQQ's plans stemming from the "Patient Experience Measurement Strategy" so that all efforts and ideas are aligned at the system, regional and local levels. This report will provide a framework for a structured and standardized approach in which recommendations such as those presented by Kuluski et al. can be prioritized.

### **Conclusion**

Improving patient experience is a key health system priority. However, Ontario is challenged by a lack of consistent, comprehensive and useful information about the experiences of its patients. To move the patient experience agenda forward, there needs to be a well-defined system level framework that sets the vision and goals by which widespread adoption occurs across the healthcare system. With adoption and a number of assessment tools in hand, the patient experience can be properly measured, monitored and reported. When alignment and transformation like this occurs, the data collected become more meaningful and the action items developed become more impactful. This process could potentially lead to improving clinical outcomes, reducing costs, improving workforce engagement and improving the patient experience. By understanding where patient experiences are suboptimal, we can begin to address gaps and ultimately improve experiences for all Ontarians.

## References

- Accreditation Canada. 2014. “Annual Report 2014.” *Patients and Families First*. Retrieved July 18, 2017. <[https://www.scc.ca/en/system/files/publications/SCC\\_AR\\_2015\\_ENG\\_Final\\_LR.pdf](https://www.scc.ca/en/system/files/publications/SCC_AR_2015_ENG_Final_LR.pdf)>.
- Anhang Price, R., M. Elliot, A. Zaslavsky, R.D. Hays, W.G. Lehrman, L. Rybowski et al. 2014. “Examining the Role of Patient Experience Surveys in Measuring Healthcare Quality.” *Medical Care Research and Review* 71(5): 522–44.
- Berwick, D. 2002. *Escape Fire – Lessons for the Future of Health Care*. New York, NY: The Commonwealth Fund.
- Berwick, D., T. Nolan and J. Whittington. 2008. “The Triple Aim: Care, Health, and Cost.” *Health Affairs (Millwood)* 27(3): 759–69.
- Bodenheimer, T. and C. Sinsky. 2014. “From Triple to Quadruple Aim: Care of the Patient Requires Care of the Provider.” *Annals of Family Medicine* 12(6): 573–76.
- Braithwaite, J., J. Herkes, K. Ludlow, G. Lamprell and L. Testa. 2016. “Association between Organisational and Workplace Cultures, and Patient Outcomes: Systematic Review Protocol.” *BMJ Open* 6. Retrieved November 13, 2017. <<http://bmjopen.bmj.com/content/6/12/e013758>>.
- Brown, A. and J. Tepper. 2015. “Patient-Centred Care: The Proving Ground for Continuity and Equity in our Health System.” *Healthcare Papers* 14(4): 4–6.
- Canadian Institute for Health Information (CIHI). 2017a. “Patient-Centred Measurement and Reporting in Canada: Launching the Discussion toward a Future State.” Retrieved July 4, 2017. <<https://www.cihi.ca/sites/default/files/document/visioning-day-paper-en-web.pdf>>.
- Canadian Institute for Health Information (CIHI). 2017b. “Patient-Centred Measurement Peer Learning Day: Translating Patient-Centred Measurement into Action.” Retrieved July 4, 2017. <<https://www.cihi.ca/sites/default/files/document/patient-centred-measurement-peer-learning-day-resource-toolkit-en-web.pdf>>.
- 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.
- Frampton, S., S. Guastello, L. Hoy, M. Naylor and M. Johnston-Fleece. 2017. *Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care*. Retrieved July 4, 2017. <<https://nam.edu/harnessing-evidence-and-experience-to-change-culture-a-guiding-framework-for-patient-and-family-engaged-care>>.
- Health Quality Ontario (HQQO). 2017. “Patient Experience Measurement and Quality Improvement Plans.” Paper presented at the OHA Patient Experience Community of Practice Webinar, June 1, 2017. Toronto, ON.
- Kuluski, K., M.L.A. Nelson, C.S. Tracy, C.A. Alloway, C. Shorrocks, S. Shearkhani et al. 2017. “Experience of Care as a Critical Component of Health System Performance Measurement: Recommendations for Moving Forward.” *Healthcare Papers* 17(2): 8–20. doi:10.12927/hcpap.2017.25415.
- Ministry of Health and Long-Term Care (MOHLTC). 2010. *Excellent Care for All*. Retrieved July 10, 2017. <<http://www.health.gov.on.ca/en/pro/programs/ecfa/legislation/>>.
- Ministry of Health and Long-Term Care (MOHLTC). 2015. *Patients First: Action Plan for Healthcare*. Toronto, ON: Queen’s Printer for Ontario. Retrieved July 2, 2017. <[http://www.health.gov.on.ca/en/ms/ecfa/healthy\\_change/](http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/)>.
- Ontario Caregiver Coalition. 2017. *Caregiver Allowance*. Retrieved July 16, 2017. <<http://www.ontariocaregivercoalition.ca/caregiver-allowance.html>>.
- Ontario Hospital Association. 2014. *Recommended Patient Experience Surveys*. Retrieved July 3, 2017. <<https://www.oha.com/data-and-analytics/patient-reported-performance-measurement/recommended-patient-experience-surveys>>.
- The Change Foundation. 2014. *Patient/Family Advisory Councils in Ontario Hospitals – At Work, in Play*. Retrieved July 2, 2017. <<http://www.changefoundation.ca/patient-family-advisory-councils-report/>>.