Patient-and Family-Centredness: Growing a Sustainable Culture

Barbara Balik

Abstract

Elements of a sustainable culture that nourishes patient- and family-centredness (PFC) in healthcare are elegantly simple, but achieving PFC poses profound challenges for healthcare systems and policy. Healthcare organizations and policy makers often identify tactics and tools that they believe enhance PFC, but they fail to involve the very people who use healthcare services: patients, their families and community members. A way of viewing the journey to a sustainable PFC culture is by examining those elements of leadership, partnership and infrastructure that are necessary for its achievement.

he journey toward delivering patient- and familycentredness (PFC) healthcare can be characterized in three stages. In the "doing to" stage, healthcare administrators and clinicians decide what's best for the patient; in "doing for," although patients' needs are prominent in program design, administrators and clinicians consult patients and families late in the process. "Doing with," however, is a collaborative approach where administrators and clinicians work in full partnership with patients and families to design and deliver healthcare that is truly targeted to patients' and their families' needs.

The "Doing To" Model

In Canada, the United States and the United Kingdom, healthcare administrators and clinicians often hold unspoken beliefs about how services should be provided, beliefs that incorporate the organization's or health professional's viewpoint, but seldom the patient's and family's. Examples of how good care is defined when systems "do to" patients and families include determining schedules and diet and limiting

"What patients want is not rocket science, which is really unfortunate because if it were rocket science, we would be doing it. We are great at rocket science. We love rocket science. What we're not good at are the things that are so simple and basic that we overlook them."

> - Laura Gilpin, Griffin Hospital, Planetree Hospital

family access in hospitals; creating systems in clinics that meet clinicians' but not patients' needs; holding conversations about care that exclude the patient and family; sharing incomplete or biased information in a way that patients and their loved ones cannot easily understand and act on; and holding a belief that care is primarily provided in healthcare settings. Terms such as "compliance" are used to describe the patient's ability to follow clinicians' recommendations. This collective mindset limits the potential for transformational change because we ignore a precious asset - the wisdom and experience of patients and families.

The "Doing For" Model

Gradual progress toward PFC is evident when leaders and clinicians move to "doing for" patients and families. In efforts to develop PFC care, patients are kept in mind during the design of facilities and programs; family presence replaces visiting hours; and clinicians recognize that patients and families are primarily responsible for care. However, it is still a stage of professional or organizational dominance - we design then ask, rather than partner with patients from the outset; we manage expectations about waiting or pain rather than asking what is of value to the patient and partnering to mutually set goals.

High levels of PFC performance lead to the development of true partnerships between patients/families and clinicians ...

The "Doing With" Model

High levels of PFC performance lead to the development of true partnerships between patients/families and clinicians – a "doing with" relationship, where all involved understand that healthcare and health transcend location. The conversation recognizes that most healthcare is actually self-care (Krueger 2011). PFC provides the foundation to achieve the "Triple Aim" - better care, better health and lower costs (Berwick et al. 2008). Krueger (2011) describes this stage as recognition that in patient-centred care, the patient/family elects to determine their location within health and care. It implies that healthcare leaders need to work with patients to develop a system for the patient's needs, not the needs of professionals or organizations. Hallmarks of PFC include mutual decision making, recognizing the assets that each partner - patient/family and clinician - brings to improved health; including patients and families as design and quality improvement partners; conveying understanding through use of health literacy; and viewing all systems through the lens of the patient/family experience.

For healthcare leaders, clinicians and policy makers, the question is, where to go from here to achieve PFC? Lessons from leaders in PFC provide the following guidance to create a fertile ground for the seeds of partnership to take root and flourish.

Leadership, Partnerships and Infrastructure

Leadership, partnerships and infrastructure are essential factors in the transformation from an organizational-centred focus to a patient-and-family-centred one.

To begin, healthcare and policy leaders, clinicians and community members need to assess current systems in light of the Doing To, Doing For and Doing With stages. Facilitated conversations about what currently exists and is accepted or

tolerated set the groundwork for moving to greater partnerships. These conversations can occur throughout the organization or the community - in an improvement team at a clinic, with patients as members; at governing boards with patient and family participation; or in regional policy committees, again with patient and family involvement. Facilitated conversations can reveal what all participants expect and what behaviours are needed to transition to partnerships.

Leadership

In their IHI Innovation Series White Paper, Balik et al. (2011) identified leadership prerequisites for an exceptional patient and family healthcare experience. In this model, governance and executive leaders demonstrate that every part of the organization's culture is focused on patient- and family-centred care, and that PFC is practised throughout. In words and actions, leaders consistently communicate that the patient's safety and well-being are the critical criteria guiding all decision making. Furthermore, patients and families are included as partners in care at every level, from policy decision-making bodies to team members providing individual care.

Balik et al. (2012) found, based on learning from exemplars and others striving for PFC, that the following seven leadership actions can create fertile ground in which to establish the PFC

- Purpose clearly describe the purpose of PFC for everyone in the organization or community.
- It's Everyone senior leaders ensure that all leaders are clear and consistent in words and actions about the purpose of
- Puzzle Maker leaders assemble the puzzle pieces so that others can see how PFC fits in the organization's overall strategy for safety, quality and financial vitality.
- Close to the Work leaders understand firsthand the barriers to achieving PFC in their organization and strive to remove them, in partnership with those who do the work and with patients and families.
- Leadership Development leaders and clinicians develop the skills to engage in successful partnerships with other clinicians, team members, and patients and families.
- Engage the Hearts and Minds of Staff and Providers hire and engage people whose values are consistent with provision of PFC, develop effective systems of care and service that enable partnerships, and ensure resources are available for continual learning and improvement.

Examples of leaders who are Puzzle Makers and Close to the Work are executives found throughout Spectrum Health, Grand Rapid, MI, in the US. Through regular purposeful leadership rounding, they engage staff and providers in conversations about PFC and links to the organization's mission. During rounds they also seek to understand the daily care environment for patients/families and staff and to actively remove barriers to effective PFC.

Partnerships

Partnerships between patients/families and clinicians are an essential component of PFC. To help forge these partnerships, three main requirements must be considered. First, knowledgeable patients and family partners must be involved in care design and improvement. Patient and family commitment to these partnerships can range from short-term participation, such as a review of patient or community education materials, to long-term, such as involvement in designing health services to better meet the needs of those with chronic conditions. If the issue at hand is about patients or healthcare delivery, consumers of healthcare should, without exception, be at the table.

A second requirement for partnerships is health literacy. Clinicians carry the responsibility for health literacy, ensuring that communication – written and verbal – is clear and understandable to patients and their families. In so doing, clinicians can empower patients and families to be more informed and capable in self-management.

A third requirement is family presence, as described fully by the Institute for Patient- and Family-Centered Care (www.ipfcc. org). Family presence ensures that loved ones are not separated during the course of care.

High-impact systems enable clinicians and others in healthcare to develop new skills and tap into the passion that led to their entering the healthcare profession.

Infrastructure

Effective systems and supportive infrastructure are essential for a successful PFC environment. High-impact systems enable clinicians and others in healthcare to develop new skills and tap into the passion that led to their entering the healthcare profession. Developing partnership skills – and these are new for most clinicians, administrators, and patients and families enables the partners to create new systems together to meet the needs of those receiving care. To realize these high-impact systems, organizations need to put structures and processes in place to ensure that patient and family partners are clear about their role, responsibilities and skills.

Achieving PFC requires significant changes in existing healthcare systems, and performance improvement systems can accelerate progress toward PFC. However, performance improvement must become deeply embedded in the infrastructure of the organization; otherwise, old patterns will continue to dominate.

More direct involvement with the patient experience of leaders in the organization also leads to important improvements. Leaders and clinicians who observe and learn from the patient's journey - across sites of care and into the community - will gain new insights that lead to designing high-impact systems.

Role Models for Progressing to PFC

Adopting these elements of leadership, partnership and infrastructure is not an instant solution, but they are important steps on the journey to PFC and true transformation in health and healthcare. The energizing story is that organizations exist that illuminate many of these essential characteristics in action. Spectrum Health, Winchester Hospital, Winchester, MA; St. Mary's Hospital, Rochester, MN; Gundersen Lutheran, LaCrosse, WI; Baylor Medical Center, Dallas, TX; Mary Hitchcock, Dartmouth, NH; and all the Planetree-designated hospitals (http://planetree.org/?page_id=260;) are among those who exemplify the best in what healthcare can become. While the organizations listed here would stress that they have far to go, they offer encouraging role models of leaders who are able to successfully grow a sustainable culture of patient- and familycentredness. HQ

About the Author

Barbara Balik, RN, EdD, is the principal of Common Fire Healthcare Consulting, senior faculty at the Institute of Healthcare Improvement, and member of the National Patient Safety Foundation Board of Governors. She is based in Albuquerque, NM.

References

Balik, B., J. Conway L. Zipperer and J. Watson. 2011. Achieving an Exceptional Patient and Family Experience of Inpatient Hospital Care. IHI Innovation Series White Paper. Cambridge, Massachusetts: Institute for Healthcare Improvement. Retrieved Öctober 24, 2012 http://www.ihi.org/knowledge/Pages/IHIWhitePapers/ AchievingExceptionalPatientFamilyExperienceInpatientHospitalCare WhitePaper.aspx>.

Berwick, D., T. Nolan and J. Whittington. 2008. "The Triple Aim: Care, Health, and Cost." Health Affairs 27(3): 759-69.

Krueger, J. 2011. "The Patient Will See You Now." Journal of Participatory Medicine 3: e53.