



EVIDENCE BOOST: A REVIEW OF RESEARCH HIGHLIGHTING HOW PATIENT ENGAGEMENT CONTRIBUTES TO IMPROVED CARE

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Improving patient experience and incorporating patient input into the design of healthcare services have emerged as critical priorities for many healthcare systems but progress has been limited. Greater engagement of patients and families in organizational roles and care teams has helped a number of healthcare organizations to improve quality, safety and patient experience. Insights from exemplar organizations suggest broader opportunities to improve health system performance. This brief provides a context and summary of research findings on case studies of patient engagement for health system improvement across organizations in four countries.

Background

Patient-centered care was identified as one of the six core goals for United States healthcare in the seminal Institute of Medicine report, *Crossing the Quality Chasm*,ⁱ and new initiatives in that country (such as Accountable Care Organizations and Patient Centered Medical Homes) are commonly judged on the extent to which they are patient-centered.^{ii,iii} In England, the National Health Service (NHS) Operating Framework describes each patient's experience as "the final arbiter of everything the NHS does."^{iv} And, in Canada, patient-centered care has been adopted as "the foundation and principal aim of the Saskatchewan health system"^v and a number of organizations in other provinces have committed to patient and family-centered care as a key part of their mission and strategic plan. Despite these health system goals, many organizations struggle to improve their patient experience scores or adopt patient-centered care policies, including less restrictive visiting hours, bedside rounding and shift reports, patient-centered discharge planning and patient access to electronic healthcare records.

Patient experience measures have been integrated into quality scorecards and reports in many jurisdictions, including many Canadian provinces. And patient-centered care has become a common descriptor of the programs and services offered in many settings. Yet, despite its growing desirability as a core attribute of healthcare, developing patient and family-centered care, and improving patient experience have been challenging for many organizations. Among key barriers are deciding what to include as the key components of patient-centered care^{vi}, the challenges involved in shifting clinician mindsets to adopt a 'patient focus' and the time required to alter the dominant culture.^{vii}

Emerging evidence does suggest that patient and family engagement translates into patient and organizational improvements (primarily in the areas of safety and effectiveness) but the mechanisms that translate patient and family engagement into better outcomes are not well understood.

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Strategies to Improve Patient Experiences of Care

Many organizations have used measurement and feedback to assess current levels of patient experience and guide efforts to improve their results. Surveys of patient satisfaction and experience have grown more sophisticated and expanded from acute care to other settings. Other methods that tap into patient views, including narratives of patient experiences, interviews and complaints, have also been developed and more widely used.^{viii ix} Today, surveys of patient satisfaction and patient experience are common in most European countries, England, the United States, Canada, Australia and elsewhere.^x However, the growing efforts to develop measures of different aspects of the patient experience have not been matched by expanding knowledge of how best to apply the results of these surveys to improving patient experience.^{xi xii xiii} Studies in several countries suggest that managers and clinicians often struggle to link these data to local improvements that might enhance patients' experiences of care.^{xiv xv xvi} While data and stories about patients are important sources of information, they may be insufficient to motivate and focus improvement in many contexts.

Providing staff with the tools and knowledge to offer patient-centered care offers a more direct route to improving patient experience. A number of organizations, including the Institute for Patient and Family-Centered Care (IPFCC)^{xvii} and Planetree^{xviii} have provided guidance on how organizations can create partnerships with patients and families, assess their current culture for patient and family centered care, and recruit, support and orient patient and family advisors.^{xix} Examples of leading practices include changes to visiting hours, involvement of patients and families in clinician rounds and shift reports, and enhanced patient input on care decisions. The Institute for Healthcare Improvement (IHI) has focused on improvements in patient experience in a variety of its initiatives, and has undertaken research on strategies to improve patient-centered hospital care.^{xx} In Canada, the Canadian Foundation for Healthcare Improvement (CFHI) has brought together health systems across the country to improve patient and family involvement in care (re-)design and measure its impact. Since 2010, CFHI has supported organizations that are involving patients and families in the design, delivery and evaluation of healthcare services. The Foundation funded a research project to determine lessons learned from 17 Patient Engagement Projects and documents promising practices in Canada and around the world.

Yet, despite all these efforts to disseminate knowledge on how to improve patient experience and patient and family-centered care, progress has not matched expectations.^{xxi}

Barriers to Improving Patient and Family-Centered Care

There are several challenges in improving patient and family-centered care and patients' views of their care experiences. One of them is the continuing lack of agreement about what constitutes patient and family-centered care and where to focus in efforts to improve care. The Picker Institute identified eight aspects of patient-centeredness through its analysis of patient experiences. These aspects include:

- (a) respect for patient preferences, values and expressed needs;
- (b) information, education and communication;
- (c) coordination and integration of care and services;
- (d) emotional support;
- (e) physical comfort;
- (f) involvement of family and close others;
- (g) continuity and transition from hospital to home; and
- (h) access to care and services.^{xxii}

This multidimensional nature of patient-centered care is also reflected in the IPFCC definition of patient and family-centered care which includes: “dignity and respect”—providers listen and honor patient and family perspectives and choices; “information sharing”—providers share complete and unbiased information in ways that are affirming and useful; “participation”—patients and families participate in care and decision-making; and “collaboration”—patients and families collaborate in policy and program development, implementation and evaluation, as well as the delivery of care.^{xxiii}

Other writers have advanced different definitions and foci for patient-centered care.^{xxiv xxv xxvi} These varying definitions for patient and family-centered care have led several authors to describe the concept as “vague” and “poorly conceptualized.” And these differences translate into different emphases and foci in their interpretation and application across professions and healthcare settings. In their review of definitions of patient-centered care, Sidani and Fox found a broad range of ideas and issues linked to patient-centered care.^{xxvii} Many physicians have come to see patient-centeredness as primarily grounded in shared decision-making for treatment options.



One study identified differences in the dimensions of patient-centered care emphasized by different clinical groups, and reported a hierarchy of patient-centeredness where social work and nursing saw themselves as more patient-centered than other professions.^{xxviii} This lack of agreement on what constitutes patient and family-centered care contributes to the lack of clarity of which aspects are key and where to focus to achieve the goal of ‘patient-centeredness’ in practice.

However, the major barriers to patient-centered care are not definitional. The key challenges focus on transforming professional work, identities and cultures. Donald Berwick suggests three critical issues that confront clinicians, managers and policy-makers. First, patients may want services that are not evidence-based and counter to the professional judgment of physicians and other providers. Second, managers and clinicians may worry that allowing patients to drive care choices may incur greater costs with fewer benefits. And third, giving patients control may mean that staff lose control over their work lives and are driven to exhaustion in the effort to meet patient demands.^{xxix}

Berwick suggests that these perceived challenges to providing patient-centered care are more apparent than real. But perceptions may be more powerful than evidence, and the issues that Berwick identifies underline a more profound concern. In the face of growing pressures to increase productivity and improve safety and quality of care, many healthcare managers and clinicians do not see efforts to change practice toward patient-centered approaches as a priority. Patient engagement to improve patient-centered care at clinical, organizational and system levels appears less pressing than other system goals.

Indeed, for many key stakeholders, patient engagement and patient-centered care are not seen as important in their own right, but are valued primarily for their impact on other, presumably more fundamental dimensions of quality, including patient safety and effectiveness.^{xxx}

Strategic Responses to Improve Patient Engagement and Patient and Family-Centered Care

The continuing challenge of involving leaders in patient engagement and patient and family-centered care has led a number of commentators to argue for the ‘business case’ supporting patient and family-centered care. They cite studies that connect performance in patient and family-centered care with performance in patient safety, clinical effectiveness and cost. For example, Jim Conway notes that, “growing research reveals the impact patient engagement can have on health outcomes, patient adherence, process-of-care measures, clinical outcomes, business outcomes, patient loyalty, reduced malpractice risk, employee satisfaction, and financial performance.”^{xxxi} Indeed, as Conway notes, a growing number of studies point to improvements in patient safety, and other outcomes.^{xxxii} However, the relationship between patient and family-centered care and improved effectiveness or patient safety is not guaranteed, and the pathways that connect these quality dimensions are not always clearly evident.

A recent systematic review of the relationships of specific patient-centered care processes and patient outcomes by Rathert and colleagues found mixed results.^{xxxiii} The researchers found that studies examining the impact of individualizing patient treatment plans to accord with patient preferences resulted in greater patient satisfaction and well-being, as did many studies that focused on improvements in communication and information provision. Yet the impact on clinical and long-term outcomes were not as clear. Some randomized studies showed positive impacts on longer term clinical outcomes; others did not. Interventions that included multiple elements of patient-centered care had better results than those that were evaluating single aspects, such as improved communications. Continuing research to discern how patient-centered care practices improve patient understanding, improved adherence with care goals and self-management will illuminate some of these issues. Beyond patient engagement in their own care, expanded efforts are needed to understand how patient engagement in

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organizational processes and patient participation in team efforts to improve care contribute to care outcomes and organizational performance.

Patient engagement occurs at several levels. Patients’ engagement with clinicians in decisions about their care through improved communications and strategies for ‘shared decision-making’ has been an important focus for research and practice. Patients and family members are also involved at the ‘microsystem’ or team level contributing to efforts to improve care delivery and at organizational and governance levels, contributing to leadership decisions on policy and practice.^{xxxiv xxxv} Microsystem and team involvement efforts offer important routes for the improvement of healthcare, including patient experience measures,^{xxxvi} and are increasingly seen as means to improve outcomes.^{xxxvii}

There have been several efforts to examine leadership and organizational factors that accompany successful efforts to create broad patient engagement and patient and family-centered care. They include research studies by Dale Shaller and Charles Darby for the Picker Institute^{xxxviii} and Karen Luxford and colleagues’

study of eight United States exemplar organizations.^{xxxix} In addition, both Angela Coulter in the United Kingdom and Barbara Balik and colleagues at the IHI have written assessments of key factors.

The two most comparable and detailed reports on organizational strategies in exemplary patient-centered organizations come from Shaller and Darby, and Luxford, both based on a sample of United States organizations. The themes from these reports are detailed in Table 1, which demonstrates the similarity in their results. Both authors note the need for leadership, partnership with patients, engagement with staff, communication and measurement. Luxford adds a few additional elements, including adequate resources for care redesign, accountability and incentives, and a culture strongly supportive of change and learning. The most critical apparent difference between these reports might be Luxford’s focus on culture—but Shaller and Darby are also clear that culture is key, saying that, “in order to achieve sustainable patient and family-centered care it is necessary to change the culture of the organization.” They view all of their key factors as supporting culture change.^{xl}

Table 1: Organizational Factors Supporting Successful Patient and Family Engagement Identified in Cross Case Analyses of US Exemplar Organizations

Author	Shaller and Danby ^{xli}	Luxford, et al. ^{xlii}
Themes	Visionary leadership	Strong committed leadership
	Dedicated champion	
	Partnership with patients and families	Engagement of patients and families
	Focus on the workforce	Sustained focus on employee satisfaction <i>and</i> Building staff capacity to delivery patient centered care
	Effective communication (across the organization)	Communication of strategic vision
	Performance measuring and monitoring	Regular measurement and feedback reporting
		Adequate resources for care delivery redesign
		Accountability and incentives
		Culture strongly supporting of change and learning

Angela Coulter’s review of the English experience suggests that these factors are broadly applicable to NHS organizations. Coulter also notes the important contributions from the involvement of doctors, senior nursing staff, patients and their caregivers, and that ‘real time’ patient survey results help to stimulate change and provide feedback on these changes to staff. She also identifies the significant role of patient stories and positive role models who refuse to tolerate poor performance.^{xliii} Balik et al also concur with the broad themes identified by the other authors. They add two additional themes: the need to focus on developing ‘reliable care’ and care that is evidence-based. Reliable care is clear, safe and well-organized care developed in partnership with patients; evidence-based care is safe and effective using appropriate technology.^{xliv}

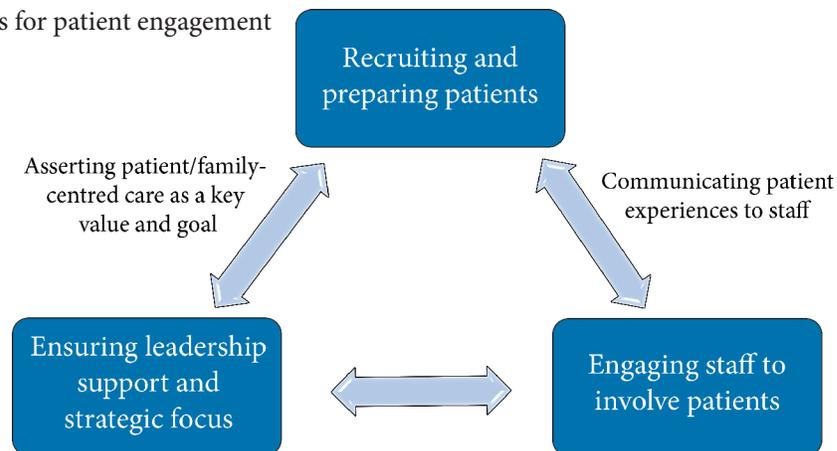
Work funded by the Canadian Foundation for Healthcare Improvement (CFHI) and carried out by a research team from Toronto, Montreal and London¹ has focused on developing a greater understanding of the dynamics of patient engagement in support of patient and family-centered care. The work has included a systematic review of patient engagement strategies aimed at improving the quality of care, repeated interviews and site visits with a selection of teams engaged in the CFHI Patient Engagement Projects, and interviews and case studies to examine efforts to develop patient engagement and patient and family-centered care in exemplar organizations. These last case studies include: two organizations in the United States

(Georgia Regents Health System and Cincinnati Children’s Hospital Medical Center); two organizations in England (Northumbria Healthcare Trust and the respiratory services in Whittington Health, an integrated trust in London); two cases based on the experiences of Canadian organizations engaged in the CFHI Patient Engagement Projects (McGill University Health Centre in Montreal and Glenrose Rehabilitation Hospital in Edmonton); along with three case studies in France (Institut Gustave Roussey, Centre hospitalier Sainte-Anne and the French Red Cross).

These cases represent a sample of leading organizations that have engaged patients and families to improve patients’ experiences of care and other performance outcomes across four different countries. A broad analysis of the learning from these case studies is underway. The analysis has focused on exploring three key dynamics in these organizations as depicted in Figure 1:

1. Strategies to recruit, orient and support patients and family members as advisors, team members and in other roles.
2. Concurrent efforts to coach and support staff working with patients and families as members of teams, councils, boards and other bodies.
3. Leadership strategies, actions and competencies needed to support patient engagement and patient and family-centered care at both the microsystem and organization levels.

Figure 1: Three key dynamics for patient engagement



¹ G. Ross Baker, Anu MacIntosh-Murray, Yvonne Bombard and Carol Fancott from the University of Toronto, Jean-Louis Denis from l’École nationale d’administration publique and Marie-Pascale Pomey from l’Université de Montréal in Montreal and Jocelyn Cornwall from the Point of Care Foundation in London, England.

Some key findings from the case studies (and interviews with other key experts):

1. **Many organizations have discovered that involving patients and families in quality improvement, patient safety and service redesign initiatives accelerates both patient engagement and the work of improvement teams.** There remains considerable variation in the approaches adopted by healthcare organizations to patient engagement and patient and family-centered care. However, linking patients to improvement efforts increases their visibility and impact, and reinforces the value of patient engagement and patient and family-centered care to staff.
2. **Patient engagement in improvement efforts may improve outcomes.** Increased patient engagement may translate into improved clinical effectiveness and enhanced patient safety. Better measurement, along with more research and demonstration projects, is needed to explore how effective patient engagement at the provider-patient, microsystem and organizational levels can influence care outcomes and organizational performance, but examples in leading organizations suggest a connection exists among these different outcomes.
3. **Effective patient and family-centered care and engagement require changes in values and relationships, but these, in turn, depend on creating structures, roles and policies that support these values and relationships.** Clinical and organizational activities need to be restructured to support patient engagement and patient and family-centered care. The failure to tangibly support this restructuring limits the ability of staff to engage and partner effectively with patients.
4. **Successful patient engagement initiatives had staff that managed local work effectively and communicated its importance, relevance and contributions to leadership.** Local champions made sure their efforts were connected to the goals, structures and processes of the organization and drew upon leadership and resources in the wider organization. Achieving success rests both on the capabilities of the team (including efforts to negotiate and interact with others, to get tasks done, secure resources and recruit involvement, for example), as well as the maturity of the patient engagement strategy and the sophistication of the broader organization.
5. **Leadership for patient engagement and to develop patient and family-centered care is critical to its success.** Leaders in the case study organizations were sophisticated and insightful practitioners who skillfully negotiated the politics and practicalities of engagement with staff, patients and families and other stakeholders. These skills and competencies will be essential if patient engagement is to play a broader role in organizational and health system transformation.

Conclusions

Providing patient and family-centered care and improving patients' experiences with their care are important health system goals. Engaging patients is key to improvements in these goals at clinician, microsystem and organizational levels. Such engagement may help accelerate efforts to improve the delivery of care using quality improvement methods. Patient engagement may be an important catalyst for improving patient outcomes and organizational performance, but the mechanisms that translate patient engagement into better care and improved outcomes are still not fully understood.

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