Improving Care *with* Those We Are Privileged to Serve: Not If but When and How

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The diverse case studies presented in this collection describe the efforts of courageous, sector-leading organizations and their staff to engage patients and families and community in reshaping and delivering care, as well as in research. We celebrate their contributions to those they serve and to the global learning healthcare community.

As a healthcare improvement executive, a professor of public health, a trustee and a patient and family member experiencing care, over the last 40 years I have witnessed efforts to harness the power of engagement and realize its potential to catalyze improvement and innovation. I firmly believe that only by engaging patients, families, the public and communities can we meet the challenges we are now experiencing in our healthcare systems as we seek to deliver the right care, in the right place, at the right time – every time.

Patient- and family-centred care is not a new idea. Parents have advocated for their children's care for decades. Since the 1970s, there have been parent/family advisory councils in pediatric hospitals, including at Boston Children's Hospital (n.d.). These parents, and their children, have made great progress, albeit along a challenging journey. Today, many organizations have embraced patients and families as partners in care – and not just in pediatrics. Increasing numbers of organizations have committed to open visitation and family engagement for all ages.

From Push to Pull

One of the important shifts in the last decade has been the transition of patient- and family-centred care from a *push* to a *pull* initiative. Historically, such care was pushed by, among others, patients/families, patient advocate organizations and accreditation. Now, the pull is dominant, because evidence shows taking that approach makes a difference. Organizations with great outcomes have a high level of patient and family engagement, and such engagement is now seen internally and externally as a hallmark of success and continuous improvement. And, yes, it is the right thing to do.

Many factors contributed to this progress. The *Crossing the Quality Chasm* report by the Institute of Medicine (IOM) was important because it defined quality as being safe, effective, timely, efficient, equitable *and* patient-centred (IOM 2001). Care cannot be high quality unless it is patient-centred. Many professional associations and early adopter healthcare organizations (several of the latter are profiled in this book) have provided the opportunity to draw courage and example from their efforts. The growing consumer movement has also had an important impact, as has patients' access to online health records and, in the US, the trend to link hospital and physician payment to patient-experience scores. Moreover, as experience with patient engagement has grown, the power of patients' contributions to creating reliable, high-quality care has been increasingly recognized.

The Dana–Farber Cancer Institute Journey

Inspired by Boston Children's Hospital and the Augusta University Health System (the latter is profiled in this collection), we started the patient- and family-centred care journey in 1995 at the Dana–Farber Cancer Institute (DFCI) after the death of Betsy Lehman, a well-respected health reporter for the *Boston Globe* who received treatment for breast cancer (Conway et al. 2006). Betsy was the wife of a cancer researcher at the DFCI and the mother of two. In 1994, she had an overdose of chemotherapy and died. That tragic experience revealed much, including system failures and our inability to listen to patients: Betsy had expressed increasing concern about the effects of her treatment, but we had not listened.

As part of our efforts to make care safer and to redesign the care environment, we invited patients and families to contribute to all aspects of the Institute. Not everyone was ready for this change, but our activities contributed to significant results: improved outcomes, safer care and improved experiences for patients, family members and staff. Today, those results are being repeated by many organizations.

Of course, research must inform practice, and busy staff need to see how patient engagement and patient-centred care enhance their daily work and the experiences of their patients. At the DFCI, we sought to identify and celebrate the "small and great wins" that emerged from greater patient engagement. One of our first small wins was the creation of a patient and family resource centre, where patients, their families and the public could find information about diseases and their treatments. Many people accessed this resource centre, and staff saw the benefit of patients who were better informed and who could more easily discuss their treatments. An even bigger win came when we put patient and family members on a committee to discuss the transfer of beds from the DFCI to Brigham and Women's Hospital. A committee comprised of members from both hospitals was created to facilitate the transfer; however, its chair was, initially, strongly opposed to including patients and family members in the discussion, fearing it might impede the careful negotiations. A few weeks later, he changed his views. The patients' reports of their experiences and their input to discussions about necessary changes made the committee's work easier, not more difficult, and members gathered valuable information they had not previously known.

Many examples illustrate how leadership is also critical to making patient and family engagement happen. At the DFCI, we did not take an organization-wide vote on whether patients should be added to committees. Instead, the governing board set as a goal the participation of patients and families in all the Institute's clinical decision-making bodies and structures, and we did just that by spreading a series of tests of change. Our experiences were guided by key learning around successful change. First, you need to *set expectations*. You then have to *position people for success* and, finally, you must *hold them accountable*. This sounds straightforward; yet, in healthcare we often do one or two of these elements, but rarely all three. At the DFCI, we worked to ensure that our patients, family members, leaders, physicians, nurses, managers and other staff were positioned for success, supported in these changes and held accountable for the results. This quickly translated into changes in behaviour among the Institute's leadership and front-line staff; so quickly, in fact, that a year after our accreditation went "conditional" following Betsy's overdose we were fully accredited "with commendation." Patient and family engagement was an essential part of that journey.

Peter Senge, the brilliant author on system thinking, introduced us to the concept of creative tension, which develops when you set a bold goal and confront that goal with current reality. Our new bold goal at the DFCI was to be, measurably, the safest healthcare organization in the US within three years. The reality was that we had killed Betsy Lehman. In the tension that subsequently arose, we saw the need to dramatically change the way in which we delivered care and to include engaged patients and families after harmful events. The DFCI was – and is – not alone in this need. Every healthcare organization in Canada, the US and worldwide, has a similar opportunity arising from a quest to prevent suffering, harm, tragedy, death and waste. Patients, families and staff all deserve respectful management of serious clinical adverse events (Conway et al. 2011). Each such event holds the potential to give leaders and staff the power to reshape how they relate to patients and families and, in partnership, how they use that knowledge to improve care and the experiences that patients and families have with their services.

Integrated Benefits of Patient Involvement

Still, some people fear that a focus on patient and family engagement might divert attention from other critical issues, including patient safety, reduction of unnecessary and expensive diagnostic tests and treatments, improvements needed to integrate care across the continuum and realization of financial goals. The experience of a number of leading organizations, however, has shown that involving patients can contribute to improvements in all these areas. The IOM issued a report a few years ago entitled *Best Care at Lower Costs*, which reviewed the evidence and experience of leading organizations (Smith et al. 2012). The authors concluded that "engaged patients are central to an effective, efficient and continuously learning system" (p. 2). Patients see issues that are not as visible to staff; their insights can contribute to developing highly reliable organizations. Involving patients and families helps to identify and focus attention on key issues. Although we have tended to see clinical outcomes, finance, service/access and experience (patient, staff) as separate issues, they are not. Each is an integrated aspect, playing off each other.

Another healthcare challenge is that most care happens in the community, not in hospitals or other organizations. A number of years ago, Lord Nigel Crisp, the former chief executive officer of the National Health Service in England, reminded me (a person with diabetes) that most of the diabetes care I receive in my lifetime will not be delivered in a hospital. It will happen in my home – in my kitchen, bathroom and bedroom. So, while we commonly think about involving patients and family members in health services within a clinic or hospital, the reality is that most care and, in particular, care for chronic conditions such as diabetes, happens in the home and is provided by patients, their family members and friends. Improving care, achieving better outcomes and reducing the costs of poor quality must be done in partnership with patients and their caregivers, or these efforts will fail. Moreover, while we have traditionally separated the role of patients in advising on changes in the hospital from their participation in broader policy discussions, there is now a closer link because improvements in population health rely on linking care in the hospital to other social determinants of health as well as the knowledge, support and behaviours that shape outcomes for populations. Growing recognition of this reality is changing the patterns of engagement. Patient and family advisory committees are now being created at a state level in Massachusetts and elsewhere to advise on health policy and health-system issues, not just on changes in hospital practice. One Canadian effort, IMAGINE Citizens Collaborating for Heath (www.imaginecitizens.ca), brought people in Alberta together to create an independent, but collective, voice to influence the future shape and focus of health and healthcare in their province.

Some Strategies and Challenges

A number of strategies will help to ensure that organizations embrace patient and family engagement as an integral part of their work. Governance, given its overall responsibility for quality and safety, plays an essential role in ensuring this development. Hospital boards set priorities, establish expectations and create accountabilities. When board members invite and listen to patients and family members, they send a clear message about the importance of engaging. Many boards are now beginning their meetings with a patient story, but the experience can be even more profound when a patient is in the room, relating his or her experiences. Boards are also now inviting former patients and members of the broader community to join quality and safety activities and committees. Others are involving patients in quality improvement and safety-walk rounds. There are dashboards that support bold aims and continuous improvement in patient- and family-centred care metrics, as well as site visits to organizations, such as those featured in this book.

Many challenges still, of course, remain. First, there is the need to recruit a broad range of patients who fully represent the community, not just those with whom we feel comfortable or who look like us. We need to include ethnic, minority and underserved populations, as well as those who are *not* currently coming through our doors (e.g., poor and disenfranchised people) in order to understand how to provide care and support the health of the populations we serve. Patient and family engagement must transform the way staff work; otherwise, it will breed cynicism. It must encompass real change, not just “check the box” exercises for healthcare executives who want to show that they are up to date. In Massachusetts, every healthcare facility must – by law – have a patient and family advisory committee (PFAC) that reports to the board of trustees. Obviously, however, just creating a committee does not ensure it will be effective or reflect patients’ views and concerns. In an effort to prevent token efforts in Massachusetts, Health Care For All (www.hcfama.org/) – the key advocacy group that had pushed for health reform in Massachusetts – publishes an annual report that compiles and records the efforts of all the PFACs in the state. Not only do the activities of Health Care For All enjoy broad support across Massachusetts, but there is an annual state-wide meeting with representatives of all these PFACs to share their efforts and identify ways to enhance their effectiveness.

Conclusions

The moral imperative to engage families began in pediatric care over 40 years ago and has been transformed into a best practice in high-performing healthcare systems, such as those profiled in this casebook, where patient and family engagement accelerates improved quality and health outcomes. We are at a tipping point where patient engagement is an essential element in creating better care, with organizations asking not "if," but "when?," "where?" and "how?" can we engage patients in the design, delivery, assessment and improvement of healthcare services.

Good work now exists in pockets across the continuum of care. We must take these individual threads and weave a fabric capable of encompassing the changes we seek to achieve across our healthcare systems. The case studies in this volume illustrate the perpetual drive for continuous improvement, whereby the values and preferences of patients and their families help to drive the difficult work of system redesign and transformation. New systems must be organized not around providers' preferences, but according to the needs of those whom we are privileged to serve. As Diane Plamping said at the Salzburg Seminar, "Nothing about me without me" (Delbanco et al. 2001).

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