The Pursuit of Genuine Partnerships with Patients and Family Members: The Challenge and Opportunity for Executive Leaders

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SUMMARY • Empowering patients to control their own healthcare experiences, sharing decisions with patients and family members, being open and transparent, and anticipating patient needs create fresh partnerships between healthcare professionals and patients. The “new rules” the Institute of Medicine (IOM) defined in its 2001 report Crossing the Quality Chasm provide guidance for leading a cultural transformation in which clinic and hospital staff truly partner with patients and their family members. The resulting experiences inspire patients to say, “They give me exactly the care I want and need, exactly where and how I want and need it” (Berwick 2009). Improved health outcomes and patients who control their own hospital stays are simple concepts that are difficult to execute. Some may view these new relationships as disruptive to clinical decision making; others may see no need to change the way they’ve always done things.

Executives are called to lead a cultural transformation—that is, to shape the views, perspectives, and behaviors of the individuals throughout their organization to achieve patient- and family-centered care. This article uses Kouzes and Posner’s (2007) leadership framework to outline how executive leaders might embrace this challenge and accomplish profound change. We support this idea with examples from our practice at the Institute for Healthcare Improvement.

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**Background and Context**

In *Through the Patient’s Eyes*, Gerteis and colleagues (1993) pioneered the idea that patient- and family-centered care requires more than just improving customer satisfaction. Instead, they ask us to take on the subjective perspective of the patient and family. This is harder than it seems. Once we shift from technical problem-solving to understanding the experiences of others, we are no longer objective observers but part of the subjective experience. The shift is difficult because most healthcare professionals believe they are already providing patient- and family-centered care. The new idea requires that they step back and ask patients and family members what matters most to them, how they want to share decision-making, how much information they would like about their clinical condition, and what unique values, needs, and preferences they want honored. Truly understanding each individual patient requires a new perspective. It takes active listening and time, which is a challenge for busy clinicians and staff.

In *Crossing the Quality Chasm*, IOM (2001) proposed six aims for improvement and ten new rules for the twenty-first century (see exhibits 1 and 2). Patient-centered care is one of the six aims. IOM (2001) defines the delivery of patient-centered care as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.” The IOM new rules lay out specific ways to redesign patient- and family-centered care: customize care according to patient needs and values; make the patient the source of control; share knowledge; allow information to flow freely; be transparent; and anticipate needs.

New research has demonstrated dramatic differences between whites and people of color in terms of patient satisfaction.

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**Exhibit 1: Six Aims for Improvement**

- Safe: no harm or needless deaths
- Effective: no needless pain or suffering
- Patient-centered: no helplessness
- Timely: no delays
- Efficient: no waste
- Equitable: for all patients

*Source: Adapted from Institute of Medicine (2001).*

**Exhibit 2: Ten New Rules to Redesign and Improve Care**

1. Care is based on continuous healing relationships.
2. Care is customized according to patient needs and values.
3. The patient is the source of control.
4. Knowledge is shared and information flows freely.
5. Decision making is evidence-based.
6. Safety is a system property.
7. Transparency is necessary.
8. Needs are anticipated.
9. Waste is continuously decreased.
10. Cooperation among clinicians is a priority.

*Source: Adapted from Institute of Medicine (2001).*
In 2007, the Centers for Medicare & Medicaid Services (CMS) proposed a standard patient experience survey called the Consumer Assessment of Healthcare Providers and Systems (CAHPS). Hospital CAHPS results would tie to payment in the Annual Performance Update from CMS. Currently, many states publicly report patient outcome and experience data. Consumers can review hospital performance and choose which hospital they use for an admission or procedure. Healthcare leaders respond to transparency in reporting and the moral imperative to improve patient and family care experiences. Viewing patients as consumers has improved customer service. For example, some hospitals now offer amenities like concierge service and valet parking, and others provide customer service training for employees. These services please patients and families, but they cannot compensate for a lack of understanding about what patients and families actually go through during a hospitalization.

To forge a partnership with patients and family, to share decision making, to put patients in control, to share openly with each other, and to anticipate patient needs requires commitment and rigor. It means challenging the status quo. This level of change requires new habits of mind and perspectives, where we become more inclusive, more permeable, more reflective, and more differentiated. Most of all, it requires leadership.

**The Leadership Challenge**

*Start before you are ready.*

—Jim Anderson, former CEO, Cincinnati Children’s Hospital and Medical Center; IHI board member

Exhibit 3: The Leadership Challenge; The Five Practices of Leadership

1. Model the way.
2. Inspire a shared vision.
3. Challenge the process.
4. Enable others to act.
5. Encourage the heart.

*Source: Adapted from Kouzes and Posner (2007).*

In *The Leadership Challenge*, Kouzes and Posner (2007) offer a framework to help executives lead such a change as moving beyond patient- and family-centered care to a partnership culture in which the patient’s voice is paramount, unique values and preferences are honored, and the IOM’s provocation to give patients control is a reality. In this culture, Don Berwick (2009, 564) would no longer fear hospitalization: “What chills my bones is indignity. It is the loss of influence on what happens to me...homogenized, anonymous, powerless, no longer myself.” By insisting that patients retain their dignity, influence, power, and unique identity, staff become collaborators in care, genuine partners who want patients to have control. This supports patients who primarily manage their illness or disease when they are away from us, at home in their own worlds. Healthcare executives can ignite the pursuit of genuine partnerships with patients and their family members to achieve extraordinary results by enacting Kouzes and Posner’s (2007) principles (see Exhibit 3).
Demonstrating Exemplary Leadership to Drive Transformation

Model the Way
Executives lead by example—they “walk the talk.” Talk openly about what you value; tell stories about how you learn from the experiences of patients and families, how you value partnering with them, listening to them, giving them control. Then demonstrate with these simple actions:

- Create a patient and family advisory board.
- Hear a family or patient story at each governing board meeting (Conway 2008).
- Put patients and families on improvement teams as team members.
- Put patients and families on hospital committees.
- Sponsor discovery dialogues where you and your leadership team listen to the high and low points of patient and family interactions with your organization.
- Launch improvements and changes based on what you learn.

As Anna Roth (2010), CEO of Contra Costa Regional Medical Center, wrote, “It is far too easy to congratulate ourselves for superficial gestures. At CCRMC we’re growing our Patient and Family Advisory Council. I find this one of the most challenging and gratifying professional experiences of my career. Much of what I have been met with at every level of the organization can be summed up as apprehension or fear. There was a prevailing concern that bringing patients and families into the room would change the conversations. This is true; it has changed the conversations for the better, a centering force that grounds us in reality. We are engaging in discussions that were out of reach for our organization previously. What we have discovered is that there is no technology or intervention that can match the acceleration of change by putting a patient or family member in the room.”

Show that you value the experiences of all clinicians and staff. Give them control over work processes, and encourage staff to customize work based on unique patient and family needs and wants. Match espoused values to actions such as sharing knowledge and letting information flow freely across the organization so that those who need it have access to it. Likewise, expect staff to be transparent with patients and to share information freely.

Inspire a Shared Vision
Start by sharing your vision of the future, a vision that includes a genuine collaborative partnership with patients and families. Envision new possibilities in patient- and family-centered care. Enlist staff and expand the common vision to include their hopes and dreams.

- Hold listening circles with staff to learn their heart’s desire for patients and family. Connect the vision with staff’s intrinsic desire to work in a helping profession.
- Create a burning platform, where dissatisfaction with the status quo becomes personal.
- Tap into storytelling. Stories of how staff successfully realize the vision and

Sadly, less than 20 percent of surveyed hospitals collect patient race and ethnicity information and tie it to patient outcomes and quality improvement.
how patients and family respond are powerful. Stories that demonstrate how staff in your organization understand the patient experience, make patients the source of control, share information boldly, and customize care for patients stoke the common fire.

• Conduct site visits to organizations that have been innovators in patient- and family-centered care.

A shared vision also works at the patient level. The CEO at Harvard Community Health Plan, Arthur Berarducci, placed a sign at the entrance of the facility that read, “Every patient is the only patient” (Berwick 2009, 560). This statement expresses the organization’s vision and commitment to customizing the care for each individual, inspiring a shared vision for all who work in the organization, and making a promise to all who receive care in that clinical setting.

Challenge the Process
Display restlessness with the status quo. Understand the problems patients and family encounter, explore their needs and preferences, and ask what exemplary patient care would look like to them. Ask about the positive moments they experienced during their hospital stays or encounters with your healthcare system. What frustrated them about being a patient or interacting with the care team? In what ways were they required to relinquish control or dignity? How did they experience anonymity?

• Develop a culture of experimentation and testing so that your organization learns how it achieves results.
• Include patient and family experiences in the design and redesign of new processes and services. Demonstrate the value to the organization of ongoing learning about the patient experience.
• Create a climate that encourages local solutions, so that staff take responsibility for giving patients more control because they believe it is essential to providing excellent care, not because they are required to do so.
• Show curiosity about small tests of change, such as Plan-Do-Study-Act cycles (IHI 2010c).
• Inquire about changes staff have already implemented. Build on small wins and make sure learning is closely tied to iterative cycles of testing and learning. Use measurement to understand improvement. As innovative approaches emerge, they catalyze ongoing improvement.
• Get an outside view. Observe and shadow patients. Seeing episodes of care as patients actually experience them is very different from the way we typically view processes.

In Transforming Care at the Bedside (Rutherford et al. 2008), an IHI collaborative learning community devoted to changing the way care is delivered on medical surgical units, we recommend that executives spend one hour per month in a patient’s room, simply observing what happens. Executive leaders experience firsthand the noise, disruption, and waiting; how information is communicated to patients; and how staff interact with patients. These observations can generate a list of improvements and innovations.

Enable Others to Act
Leaders cannot lead alone; they need support and action from everyone in the organization. Leaders must release the
creativity and know-how not just of staff but also of patients and family members. Collaboration requires trust and teamwork.

- Make patient and family partnerships a strategic priority equal to patient safety initiatives and sound fiscal management.
- Sponsor teams to accomplish the transformation.
- Include staff, patients, and family members on teams to leverage talent and expand perspectives on problems and solutions. Show commitment to inclusion so that all may act to accomplish the vision.

Encourage teams to improve patient and family partnerships and to test their ideas. Success builds competency and breeds more success. As teams execute better ideas and make improvements, their confidence in their own influence also increases.

**Encourage the Heart**
A leader’s passion fuels improvement.

- Tap into the enthusiasm of others to drive change.
- Recognize teamwork and the individual contributions of others.
- Celebrate successes and milestones along the way.

Leaders who get extraordinary results acknowledge individuals who enact and embody the organization’s vision and values—in this case, to improve patient and family partnerships, to make patients the center of control, and to share information freely with them. This is best done by sharing exactly what the individual did that reflects values in action, by giving what Kegan and Lahey (2001) call “ongoing regard”—that is, acknowledgment of specific, admirable actions as opposed to empty praise and vague attribution.

Public celebration of improvement reinforces the commitment to change. Minor change is difficult. A complete transformation is even harder, because it is more radical and requires fresh thinking and experimentation. Staff may grow weary along the way. Celebrations publicly recognize the accomplishments and contributions of team members. When patients and family are included in celebrations, they serve as vivid reminders of the profound purpose of the work.

**Innovations to Advance Genuine Partnerships with Patients and Family Members**
Although all the rules for the redesign of the healthcare system outlined in IOM’s (2001) *Crossing the Quality Chasm* would help to achieve truly patient-centered care, four of these rules are particularly relevant to achieving genuine partnerships between clinical caregivers and patients and their family members. These are not merely projects to be implemented; rather, they are innovations that reflect the cultural transformation whereby true partnerships with patients and family members are actualized at all levels of the organization.

**Care is customized according to patient needs and values.**
The system should be designed to meet the most common needs, but it should include the capability to respond to individual patient choices and preferences (IOM 2001).
• **Open visitation and family members’ participation in care.** Pediatric hospitals lead the way in this aspect of patient- and family-centered care, providing sleeping accommodations for parents and encouraging them to participate in their child’s care. Many adult hospitals now see the value of having loved ones nearby for support and involving them in meeting some of the patients’ physical care needs. A growing trend in intensive care units across the country is the elimination of visit restrictions, where family members are welcome 24/7/365. Geisinger Medical Center in Pennsylvania is one example of a facility that has implemented open visiting hours hospital-wide (IHI 2010a).

• **Patients establish daily goals.** As Scott-Smith and Greenhouse (2007) describe in “Transforming Care at the Bedside,” nurses on medical and surgical units routinely ask patients and family members to establish daily goals—in other words, the concerns they want addressed and the most important thing that they want to accomplish that day. The patient’s goals for the day are posted on a white board at the bedside to facilitate communication with all members of the care team.

• At first, nurses (or other members of the care team) might be reluctant to ask patients to voice their explicit needs—they may assume that they know what the patient needs, or they may fear that they are unable to honor their requests. Customizing care to meet the unique needs and preferences of every patient requires the commitment of the entire care team and the support of every department.

• **The patient is the source of control.** Patients should be given the necessary information and the opportunity to control healthcare decisions that affect them. The system should be able to accommodate differences in patient preferences and should encourage shared decision making (IOM 2001).

• **Patient- or family-activated rapid response teams.** Traditionally, healthcare providers have activated codes—and more recently, rapid response teams—to summon a team of doctors and other healthcare team members to the patient’s bedside. As healthcare systems begin to engage patients as partners rather than simply recipients of care, new paradigms are emerging. At the University of Pittsburgh Medical Center (UPMC) Shadyside campus in Pittsburgh, Pennsylvania, part of that new paradigm is a program called Condition H (for Help), in which family members can call for immediate help if they have concerns that aren’t being addressed or to alert the care team of clinical changes that require medical attention (IHI 2007; UPMC 2010a).

• **Patient choice in meal selection.** At UPMC Shadyside, the patient-controlled liberalized diet program allows patients to make their own food choices while in the hospital, even when they would typically be on restricted diets. This approach not only improves patient satisfaction, it also gives caregivers the opportunity to provide ongoing nutrition education based on the patient’s meal choices (Rutherford et al. 2008; UPMC 2010b; Scott-Smith and Greenhouse 2007).
• **Patient/family participation in change-of-shift report and multidisciplinary rounds.** Diane Plamping has proposed the maxim, “Nothing about me without me,” which calls for a level of transparency and participation of patients and family members that is uncharacteristic of most hospitals and other clinical settings. (Berwick 2009, 560; Del-Banco et al. 2001). Offering opportunities for patients and their families to fully engage in multidisciplinary rounds and change-of-shift reports are two ways to create true partnerships in the planning and evaluation of an individual's care and ritualize shared decision-making.

• Many hospitals have initiated multidisciplinary rounds in intensive care units, which bring the members of the care team together to plan and evaluate the care provided to each patient. This model ensures a high level of communication and collaboration among doctors, nurses, and others involved in developing daily goals for every patient every day. Some hospitals have successfully invited families into their regular rounding process. “We include parents in clinical rounds not because we believe in patient-centered care, but because we believe in great care, and we can't deliver great care if the person who knows the patient best isn't in the room,” says Mark Helfaer, MD, Chief of Critical Care at Children's Hospital of Philadelphia (IHI 2006).

• Most hospitals that participate in Transforming Care at the Bedside collaboratives have begun to include patients and family members in nurses’ change-of-shift reports and multidisciplinary rounds to customize care to patients’ values, preferences, and expressed needs and to engage them in shared decision-making (Rutherford, Moen, and Taylor 2009, 14). Cedars-Sinai Medical Center in Los Angeles and Wentworth-Douglas Hospital in Dover, New Hampshire have successfully implemented innovative models for bedside rounding and change-of-shift reports (Hain 2009; Chapman 2009). As part of its transition to electronic medical records, Kaiser Permanente has developed a Nurse Knowledge Exchange computer program, which allows departing nurses to create customized electronic reports on patients, including lab results or medication changes, for the incoming nurses. The nurse coming on duty also makes bedside rounds with the outgoing nurse and engages patients and family members when possible in a discussion of treatments and progress (Fahey and Schilling 2007; IHI 2005).

**Knowledge is shared and information flows freely.**

Patients should have unfettered access to their own medical information and to clinical knowledge. Clinicians and patients should communicate effectively and share information (IOM 2001).

• **Access to medical records.** Many physicians and other healthcare professionals are concerned that patients will be worried and confused by medical jargon they don't comprehend. Some attorneys are concerned that allowing individuals full access to their medical records could give dissatisfied patients fuel for malpractice claims. A review of published research found that patient-
accessible medical records had the potential for modest benefit in enhancing doctor–patient communications, while the risk of increasing patients’ worries or confusion appeared to be minimal (Ross 2003).

- True partnerships with patients and their family members mean giving them unrestricted access to their own clinical information. This can provide opportunities for better collaboration between clinicians and patients and for clarification of clinical information and treatment plans (Halamka, Mandl, and Tang 2008).

- **Providing effective teaching and facilitating learning.** Far too often, patients and family caregivers do not understand what clinical staff have taught them about their conditions and how to care for themselves when they go home or to other care settings. The Institute of Medicine (2003) has defined health literacy as “the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.” A growing body of evidence outlines effective approaches to increasing health literacy in various patient populations.

- Many clinicians overestimate their patients’ understanding of clinical information and instructions for self-care. Clinical staff should shift their focus from what they have taught the patient and family caregivers to what the patient and family understand. Using clear communication techniques, clinicians can help patients understand their conditions and follow care instructions for better health outcomes. Patient education programs such as Ask Me

3 (www.npsf.org/askme3) are designed to promote communication between healthcare providers and patients.

- Clinicians should use the “teach back” method to assess the patient’s and family caregiver’s understanding of clinical information and instructions. In this method, providers ask patients and family to repeat the information *in their own words*. If the patient is not able to repeat the information accurately, providers should rephrase the information rather than just repeat it. Then, providers should ask the patient to repeat the instructions again to assess their comprehension (Pfizer 2008).

- These approaches to improving patients’ and family members’ understanding of self-care are being adopted in many healthcare settings. The STate Action on Avoidable Rehospitalizations (STAAR) program, an initiative of the Commonwealth Fund and the Institute for Healthcare Improvement (IHI 2010c), and the Society for Hospital Medicine’s (2008) Project BOOST (Better Outcomes for Older adults through Safe Transitions) recommend that their participants use health literacy principles to enhance patient education and discharge preparations during acute care hospitalizations.

**Needs are anticipated.**

The system should anticipate patient needs, rather than simply react to events (IOM 2001).

- **Conduct observations of patient experiences.** Senior Executives at Iowa Health System have gained significant insight into what patients experience during a
hospital stay by spending an hour with a patient (at his or her bedside, during diagnostic tests, in the emergency department, etc.) each week. One executive reported that she learned more from a single hour of observation than the entire executive team learned during regular walk rounds. This approach of conducting weekly in-depth observations helps executive leaders to truly understand patient experiences and better equips the executive team to work with improvement teams to anticipate and meet the routine needs of patients in their care (Iowa Health System 2010a; 2010b).

- **Observe Peace and Quiet Time.** Another practice many hospitals adopted as part of Transforming Care at the Bedside is called “Peace and Quiet Time” or “Quiet Time.” At the University of Kansas Hospital in Kansas City, Kansas, Quiet Time is a dedicated time when lights are turned down and noise and activity are restricted on a unit so that patients may experience a quiet, restful period each day. This approach encourages patients to rest to help in their recovery (Boehm and Morast 2009; Robert Wood Johnson Foundation 2008).

### Conclusion

‘Patient-centeredness’ is a dimension of health care quality in its own right, not just because of its connection with other desired aims, like safety and effectiveness. Its proper incorporation into new health care designs will involve some radical, unfamiliar, and disruptive shifts in control and power, out of the hands of those who give care and into the hands of those who receive.

—Don. Berwick

Executive healthcare leaders show what they value through their actions and by where they turn their attention. Making genuine partnerships with patient and family members a strategic priority sends a strong signal. The declaration that patient- and family-centered care has the same strategic value and importance as patient safety and sound financial management resounds from the hospital board to front-line clinicians and staff—and ultimately to patients and family members, who spread the message that we give patients and their family members exactly the care they want and need, exactly where and how they want and need it.

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