Buyers and consumers of healthcare are becoming more sophisticated, both individually and in aggregate. Most patients now do their own research about a procedure or illness or, at the very least, have friends and family members do it for them.

Patients want to be cared for and cared about. Given their tremendous interest in the care they receive, patients and their loved ones are acutely aware of how it is provided. They immediately sense whether healthcare professionals care about them on a personal level; whether the processes involved in delivering care are coordinated, efficient, and focused around them; and whether an organization has the big picture and is “getting it right.” Therefore, individuals receiving care are in a very good position to help an organization identify areas of potential harm and partner with it to prevent such errors.

Ignoring the input of patients and their families is like trying to win a hockey game with one key player in the penalty box. Patients bring a unique perspective to the development of a safety culture, and, without their input, an organization is operating without its full compliment of resources. This involvement can lead to better approaches to patient safety, as communication between staff and
patients is completely open and thus errors can be discussed and, in many cases, prevented.

Organizations should involve patients and families in efforts to reduce harm and error for several reasons, including the following:

- Patients and their families help organizations develop new perspectives, as patients experience gaps and fragmentation in systems firsthand.
- Patients and their families keep healthcare professionals and organization leaders honest and grounded in reality.
- Because they are the recipients of care, patients, by conveying their opinions and feelings, can inspire and energize staff to commit to change.
- Input from patients and families can help improve quality and safety as well as staff satisfaction.

While involving the patient in preventing error may seem a little scary, risk management literature supports patient- and family-centered principles (Hebert, Levin, and Robertson 2001). Involving patients and their families in improvement efforts has been shown to reduce the likelihood of malpractice allegations (Wissow 2004). Communication breakdowns are one of the main reasons that patients sue a healthcare organization after an adverse event (Alaszewski and Horlick-Jones 2003). Many times, patients sue because practitioners fail to understand patient and family perspectives, deliver information poorly, devalue patient and family views, and withhold information, thus deserting the patient and family in their time of need (Gerteis et al. 1993; Cleary and Edgman-Levitan 1997; Larson et al. 1996; Cleary 2003; Frampton, Charmel, and Gilpin 2002). By involving the patient and family in improvement efforts, practitioners establish an environment of open and honest communication, thus reducing the need for malpractice proceedings. A more in-depth discussion of the importance of communication with patients can be found in Chapter 6.
HOW TO INVOLVE PATIENTS IN THE SAFETY IMPROVEMENT PROCESS

Organizations that involve patients and their families at every level of the care delivery process can maximize the contributions of a valuable resource and take one step further toward high reliability. While this may seem obvious, many organizations develop care programs without thought to the recipients of that care. Patients and their families can be involved in many ways in a safety culture. The following sections provide some guiding principles and tips for organizations in developing a patient-centered safety culture.

Obtain Patient Feedback

Obtain patient and family feedback from a variety of sources and synthesize that feedback in one place. Some areas from which to obtain patient and family feedback include the following:

- Surveys
- Focus groups
- Walk-throughs
- Compliment/complaint letters
- Safety hotlines
- Staff feedback
- Community groups

Partner Patients with Healthcare Professionals

Partner patients and families with healthcare professionals to set policies, design programs, and establish priorities for continuous improvement. This may seem like a Herculean task; however, organizations that do this reap tremendous benefits. One way to
accomplish a partnership program is to develop patient and family advisory councils. These councils are typically composed of 12 to 30 patients and family members who meet regularly to propose and develop programs, policies, and services. An example of a successful patient and family advisory committee is discussed in Sidebar 5.1.

**Use Patients as Faculty**

Use patients and families as faculty for healthcare professionals and employees. Because patients are the direct recipients of care, they can provide unique input to the training process. Organizations can use them to help with employee orientation, share experiences with inservice programs, and teach medical students and house staff about partnership and disclosure.

**Create Patient-Caregiver Joint Quality Initiatives**

Have patients and caregivers jointly define quality goals for illness management. Involving patients in their care helps them understand their illness and their treatment and recognize when treatment deviates from the norm. This can help patients to identify errors and point out inconsistencies. Organizations can involve patients in their care by taking some of the following steps:

- **Sharing care plans.** Care plan sharing can be accomplished through continuous discussion by physicians and nurses about the type of treatment a patient needs and the state of his or her recovery.
- **Reviewing daily goal sheets.** A daily goal sheet outlines every goal for a particular patient for a particular day. These goals may be clinical in nature or more social. An example of a clinical goal is to have a patient removed from his or her
ventilator by the end of the day. A social goal might be to ensure the patient's ability to watch his or her favorite television show. Whatever the goals listed on the daily goal sheets, the clinicians should discuss and review them with patients and their families. Patients and families, in turn, should be able to contribute to goal development. In addition, the daily

Sidebar 5.1. The Dana-Farber Patient and Family Advisory Council

In January 1998, the Dana-Farber Cancer Institute, located in Boston, created a patient and family advisory council (PFAC) that was designed to provide input, develop improvement programs, and serve as a resource of patient and family opinion. The council was composed of 15 patients and family members who served one-year terms renewable for up to three years. Members participated in staff project teams and standing hospital committees, such as care improvement and clinical quality and safety committees, and initiated their own projects, such as a patient-staff newsletter. One of the initiatives tackled by PFAC involved minimizing clinical wait times at Dana-Farber’s outpatient clinics. Prior to the initiative, wait times ranged from 45 minutes to 3 hours. Council members polled schedulers, conducted an observational study, and concluded that the clinics were overbooking patients between the times of 10 a.m. and 2 p.m. The council proposed the following improvements to address this issue:

- Correct scheduling templates.
- Stop overbooking practices.
- Adopt scripts to explain to physicians and patients the limited availability of midday appointments.
- Implement scorecards to track times regularly.

The final outcome of this initiative was that the amount of time that patients wait before their visit for treatment gets underway was reduced by more than 25 percent.

Source: Dana Farber Cancer Institute, Boston.
goal sheet should be posted on a patient’s bed or on the door of his or her room. This way, all staff associated with the patient’s care can be aware of the patient’s goals for treatment.

- **Engaging in bedside rounds.** Bedside rounds can be conducted at shift change to ensure that the new shift understands the needs and condition of the patient and his or her family.

When involving patients in their care decisions, it is important to verify that they understand the topics being discussed. According to the 1992 National Adult Literacy Survey, more than 20 percent of adult Americans are functionally illiterate and read at or below a fifth-grade level. An additional 25 percent of adults are only marginally literate (Kirsch et al. 2001). These 90 million adults have difficulty understanding healthcare information such as consent forms, medicine labels, written care instructions, and appointment schedules. Asking patients if they understand is not enough. To ensure that information is understood, staff can ask patients to verbally summarize the information. Should a literacy problem be discovered, staff can overcome it by using other forms of communication besides written material. Audio or video technology can help address the needs of illiterate patients.

The American Medical Association developed the Health Literacy Kit in 2001 to raise awareness of low health literacy among patients and help organizations improve methods of patient communication. An expanded version of that toolkit, the 2003 Health Literacy Educational Kit, is now available. More information about this kit can be found at www.ama-assn.org/ama/pub/category/9913.html.

**Never Separate Patients from Their Family**

Never separate the patient and family unless the patient requests it. Medical procedures are scary enough, but being separated from loved ones who can provide support makes even routine procedures seem scarier. Organizations that include families in the care of
patients see improved clinical outcomes as well as increased quality of care. Some ways that organizations can include families in the care of a patient follow:

- Keep nursing units, intensive care units, and the emergency room open to families 24 hours a day, including during shift changes, rounds, codes, and other emergency situations. This may seem like a tall order, but some organizations have operated this way with great success. Intensive care units that are designed to allow families access any time have actually decreased the potential for error and increased patient safety. Along the same lines, those organizations that allow family members to stay during anesthesia induction, in the recovery room, in radiology, and during treatment and procedures open up the environment to transparency and reduce the potential for errors.

- The primary family spokesperson can be given an identification card so that all organization staff is aware of his or her status. This individual can be provided meals, discounted parking, and training to support and teach him or her how to help the patient during treatment and recovery.

Identify the Need for Emotional Support

Staff should be aware of patients’ and families’ emotions at each step of a process. Organizations should educate staff about how to address patient anxieties and provide talking points for common yet difficult conversations.

Never Deny the Patient Information

Never deny the patient and family information unless the patient requests it. Because patients are the individuals receiving care, they
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should be as involved as they want to be in that care. Several creative methods can be used to provide information to patients. Following are a few suggestions:

- Offer the medical chart to the patient for review. Individuals can confirm allergies and identify any missed or incorrect items on their medical history.
- Orient the patient and family to the unit, equipment, and team members. This should be done on admission to a new unit or practice and can also take place when new equipment is introduced or during shift change.
- Offer families ways to keep in touch with the clinical staff, such as e-mail, beepers, voice mailboxes, and telephones. For example, to ensure a patient and his or her family are up to date on the patient’s condition, a clinician can use a voicemail system that allows him or her to record a message about the patient’s status every 12 hours, which family and friends of the patient can check periodically. In addition to providing open communication with the family, this system helps reduce the number of calls from family and friends to the nursing station, thus decreasing the number of interruptions and distractions at the nursing station and improving the quality of care.
- Use wipe boards to enhance communication. These dry-erase boards can be used in the patient’s room or wherever information between staff and patients needs to be communicated. Staff can list the name of the doctor, nurse, and other staff on the board, and family members can write questions on it to ask the doctor when he or she next visits.
- Share clinical pathways with patients and families. Clinical pathways are recipes of how care should be delivered. By sharing these, patients not only know what to expect from their care, but they can also help identify when the pathways are not followed; this can help prevent an error. For example, a clinical pathway for a joint replacement patient’s care would be that he or she will receive an evaluation by a physical therapist before
discharge. Should this evaluation not occur, the patient can ask about it, thus avoiding a potential mistake.

- Always provide all test results. Many organizations only provide test results if the results require further medical attention. For example, a pregnant woman may not hear that her test for gestational diabetes came back negative. This practice is dangerous and should be avoided. All patients have the right to know the results of all tests. In addition, if a patient knows he or she is going to hear about test results, he or she can question when results are not given and thus avoid the problems that arise from lost or misplaced results. Organizations that are using web-based medical records can now have patients log on to the system and check their own test results. The patient is motivated to check them; who else is more interested in the results than the person whose health is affected? By allowing patients access to their records, these organizations can avoid playing telephone tag and multiple wasted calls for the office staff and clinicians.

- Offer families and patients scheduled conferences with an interdisciplinary team to discuss care. This ensures that all parties involved are working from a common understanding and that questions do not get lost.

- Provide question cards for patients and families. These cards allow people to write down their questions before a doctor visit. They can be given or e-mailed to physicians prior to a visit so that the doctor knows what is on the patient’s mind and can address it. These cards prevent important information from being omitted.

- Customize discharge instructions, and make sure the patient and family know who to call if they have questions.

Not only should organizations not deny patients and their families information but they also must empower patients and families to ask questions. Questioning a doctor or nurse is intimidating, and many, if not most, patients and families may be reluctant to do so.
Organizations that emphasize consistently that questioning any clinician or staff member is appropriate will obtain the greatest participation from patients and thus reap the most benefits. Some creative ways to solicit questions include the following:

- Have staff wear buttons that encourage patients and families to ask questions. These could read, “Ask me to check your armband,” or “Ask me if I’ve washed my hands.”
- Provide tent cards in patient rooms with a phone number for a problem hotline for patients and families.
- Develop pamphlets, brochures, or posters that address how patients can be involved in their care. One source for tips to include in these materials is the Joint Commission’s Speak Up Campaign (www.jcaho.org/generalpublic/patientsafety/speakup/speakup.htm); another is the Agency for Healthcare Research and Quality’s “5 Steps to Safer Health Care” (http://www.ahrq.gov/consumer/5steps.htm).

**NOTHING ABOUT ME WITHOUT ME**

First suggested by an English midwife in 1998, the phrase “Nothing about me without me” exemplifies the movement toward involving patients and families in patient safety efforts. Acting on this philosophy, the National Patient Safety Foundation (NPSF 2003) produced *National Agenda for Action: Patients and Families in Patient Safety*, a public call to action to provide a roadmap for efforts in the following four areas:

1. *Education*. NPSF provides a central clearinghouse and resource center for patient safety training resources, and organizations are encouraged to establish interactive, interdisciplinary education programs that bring together patients and professionals.
2. **Culture.** NPSF’s annual congress in May provides a forum for sharing and disseminating information about culture change and other strategies to improve safety. The Stand Up for Patient Safety members also share information and strategies about this at their events. Organizations are encouraged to move toward a safety culture. As part of this culture, they can incorporate patient representatives for advocacy, implement patient and family advisory councils, incorporate patient and family representation on boards of trustees, and develop patient safety task forces.

3. **Research.** NPSF funds research studies annually, including studies that examine how to disclose medical errors to patients and how to involve patients and families in improving safety.

4. **Support services.** Support services will be structured to help patients and families who have experienced a medical error. NPSF is working in partnership with its Patient and Family Advisory Council to identify a reliable source of funding to support the national resource line center and information line. Organizations are encouraged to foster localized support groups and disclosure and communication programs.

**CONCLUSION**

For an organization to be considered highly reliable, patients and families must be partners in promoting patient safety. Healthcare organizations cannot afford to ignore this most natural resource. Organizations that create opportunities for patients, families, and staff to work together can improve the safety and quality of the care experience. Leadership must embrace the concept of patient and family inclusion, promote it among staff and patients, and invest in training to build the collaborative skills of all involved.
REFERENCES


