Patient and Family Involvement in Contemporary Health Care

Peter Angood, MD,* Jennifer Dingman,† Mary E. Foley, MS, RN,‡ Dan Ford, MBA,§ Becky Martins,∥
Patti O’Regan, ARNP, ANP, NP-C, PMHNP-BC, LMHC,¶ Arlene Salamendra,**
Sue Sheridan, MIM, MBA,††+++ and Charles R. Denham, MD§§§§

Objective: The objective of this article was to provide a guide to health care providers on patient and family involvement in health care.

Methods: This article evaluated the latest published studies for patient and family involvement and reexamined the objectives, the requirements for achieving these objectives, and the evidence of how to involve patients and families.

Results: Critical components for patient safety include changing the organizational culture; including patients and families on teams; listening to patients and families; incorporating their input into leadership structures and systems; providing full detail about treatment, procedures, and medication adverse effects; involving them on patient safety and performance improvement committees; and disclosing medical errors.

Conclusions: The conclusion of this article is that, for the future, patient and family involvement starts with educating patients and families and ends with listening to them and taking them seriously. If patient and family input is emphatically built into systems of performance improvement, and if patients and families are taken seriously and are respected for their valuable perspectives about how care can be improved, then organizations can improve at improving. Resources in health care are in short supply, yet the resources of patient and family help and time are almost limitless, are ready to be tapped, and can have a huge impact on improving the reliability and overall success for any health care organization.

Key Words: patient, family, involving patients, involving families, patient-centered care

(J Patient Saf 2010;6: 38–42)

A VISION

An integrated health care delivery and academic support system that has alignment of all its essential components, organized on a continual renewal cycle for successful and consistent functioning across the continuum of clinical care; professional education and research, high-quality and well-funded academic pursuit, and the provision of a nourishing balanced environment for clinicians, staff, and students, are considered major priorities in a safe, reliable, and durable system that promotes human wellness and the optimal return to wellness when disease occurs—always in a fashion that ensures dignity and respect from birth to death.

CURRENT STATUS

An epiphanic moment about the condition of American health care occurred nearly a decade ago with the publication of the Institute of Medicine’s (IOM) landmark report To Err Is Human.1 After this report, in the classic Donabedian sense (structure, process, and outcomes), there is now a much-improved recognition of the types of structures and processes that are potentially useful to facilitate health care, achieving its next stage of maturity. Unfortunately, the anticipated positive outcomes are not consistently recognized or obtained, and significant problems remain with the underuse, overuse, and misuse of health care resources. As an industry, health care does not inherently have expertise with the intricacies of organizational process improvement strategies, systems design, or re-engineering and the integration of human factors engineering. The net result is that fragmentation of effort persists and that a cohesive set of improvement strategies has not emerged to date.

Primarily based historically on professionalism and education, the health care system evolved to a mosaic of cottage businesses that have organically developed, through great procedural innovation and a microtransaction financial reward model, to the current revenue-focused, production-centered model of care. Unfortunately, fragmented and inconsistent integration along a patient’s trajectory of care is only too common. Production-centered care does not always take the individuality of each patient into consideration, and may create the potential for unsafe care—the so-called quality chasm. Another IOM landmark report, Crossing the Quality Chasm, articulated the following principle, critical to closing this gap: “...the healthcare system must be redesigned to be evidence-based, patient-centered, and systems-performance-focused.”2

The IOM has defined the essential dimensions of patient-centered care to include, but not be limited to, customized information, communication, and education; coordination and integration of care across conditions and settings, and over time; shared decision-making of clinicians with patients and families; self-efficacy and self-management skills for patients; patient’s experience of care; effective provider-patient partnership; and enhanced cultural competence of health care providers.3,4 A critically important stage of any health care organization, therefore, should be to improve the reliability of its care to achieve the following IOM goals: to make care safe, effective, efficient, patient-centered, timely, and equitable. These are now accepted as contemporary core quality components for health care.

From the *National Quality Forum, Washington, District of Columbia; †Persons United Limiting Substandards and Errors in Healthcare, Pueblo, Colorado; ‡Center for Research and Nursing Innovation, The University of California at San Francisco, San Francisco, California; §First Group, Oro Valley, Arizona; ||Voice for Patients, Warren, Maine; ¶Nurse Practitioner, Port Richey, Florida; **Families Advocating Injury Reduction, LaGrange, Illinois; ††Patients for Patient Safety, World Health Organization, Geneva, Switzerland; †††Texas Medical Institute of Technology, Austin, Texas; and; §§§Harvard School of Public Health, Boston, Massachusetts.

Correspondence: Charles R. Denham, MD, Texas Medical Institute of Technology, 3011 N Interregional Hwy 35, Austin, TX 78722 (e-mail: Charles_Denham@tmit1.org).

Funding support for this article was provided by Texas Medical Institute of Technology.

Copyright © 2010 by Lippincott Williams & Wilkins
Patient advocacy experts and leaders believe that, once this initial step is achieved by organizations, the whole-person approach can then be better addressed through an integrative care strategy that uses contemporary clinical care, and by adding selected complementary care methods that are evidence-based. There is strong evidence that an integrative care strategy can heal and improve basic conventional care by addressing the mind, body, and spirit connection, and that integration into safe practices can help healthcare organizations better learn to use patients and families to increase patient-centered care.

One patient safety advocate, and patient, who has experienced metastatic cancer and been a “frequent flyer” in many hospitals, states that what patients want is very simple: “Know me, love me, and make it simple” (Moose Millard, oral communication, August 1, 2006). “Know me” means that every effort needs to be made to have the information available about a patient when (s)he has contact with a healthcare organization. Fear and a sense of threat loom when this aspect of care does not occur for patients. “Love me” means showing simple compassion at the front line, which goes a long way to cover any shortfalls in organizational performance. “Make it simple” means that current system designs make the clinical experience difficult for patients, and helping to simplify these systems designed around clinical production silos is greatly appreciated by patients and families.

Importantly, collaborative initiatives such as the National Priorities Partnership, a collaboration of 32 national stakeholder organizations, have recognized the importance of harmonizing efforts into uniform strategies that will simplify the external influences on healthcare organizations. The National Priorities Partnership has identified 6 key priority areas: (1) patient and family engagement, to ensure that patients and their families have access to tools and support to be fully informed about and have a role in making healthcare decisions; (2) improved population health; (3) increased patient safety by eradicating preventable medical errors; (4) well-coordinated patient-centered care across the continuum of care; (5) increased access to hospice and palliative care services for patients who are diagnosed with severe illnesses, and those facing the end of their lives; and (6) elimination of overuse of unnecessary or risky care and bringing greater focus to efficient, appropriate, preventive care. Clearly, patients and families have a critical role to play in each of these emerging priority areas.

Similarly, specific organizations such as the National Quality Forum (NQF) continue to pursue a number of initiatives that focus directly on patient safety. For example, early in its first decade of existence, NQF initiated the Safe Practices program and has continued to update the program on a regular basis. The program now embraces 34 evidence-based Safe Practices that are proven to help improve patient safety and quality of patient care. Ongoing implementation of these practices and their uptake by numerous organizations is proving to be a valuable national resource. Of particular importance, the latest update to the program provides specific information about how to involve patients and families in the implementation of each Safe Practice. Moreover, a consensus process was undertaken during the development of the practices with input from many patient advocates who significantly contributed to their development.

Patient advocates do not believe that there are shortcuts to improved quality without first making care safe. There is a recent trend toward improved transparency in healthcare, perhaps energized in part by pay-for-performance, which is demonstrating the complexity of healthcare but also revealing substantial patient safety gaps, especially in hospitals. For healthcare research is also beginning to demonstrate a direct correlation between quality of care and patient satisfaction—leading to the belief that characteristics of hospitals that are more reliable in delivering clinical quality are intrinsically more likely to deliver a better patient experience. This should not be a surprise, because customer satisfaction is almost always coupled with a higher quality of service provided in other industries, such as airlines and consumer goods.

FOCUS ON CRITICAL COMPONENTS

The lead chapter in the current version of the NQF Safe Practices Report focuses on improving patient safety by creating and sustaining a culture of safety. The first 4 Safe Practices from this chapter collectively provide numerous specificizations and practical implementation suggestions in this regard. The remaining 30 NQF Safe Practices are organized in other chapters to facilitate an integrated approach to improving patient safety. In addition to the opening chapter, focused on the culture of safety, other chapters include topics on:

- Informed consent, life-sustaining treatment, disclosure, care of caregiver
- Matching health care needs with service delivery capability
- Facilitating information transfer and clear communication
- Medication management
- Healthcare-associated infections
- Condition- and site-specific practices

Together, a road map for improvement is laid out while simultaneously providing the emphasis for engagement by patients and family members. It is the patients and families who ultimately benefit from integrated approaches that the Safe Practices represent. Examples are highlighted in the following sections.

Culture is the collective behaviors of an organization, or what some have described as “what people do when no one is looking.” It reflects the operational values of the organization, which may not necessarily be those espoused in brochures or on the walls of the lobby. The patient’s experience has been a long-ignored issue in some organizations and of lower priority in others, and at least until recently, it has been linked to payment. Patient expert advocates state that it is important that caregivers ask for the patient’s and family’s feedback on care and level of satisfaction concerning their sense of being listened to, included on the team, and communicated with, in a full, open, and honest way. It is critical for leadership to answer the questions: “What does an effective listening environment look like, and where are we measuring up to that vision?” (Mary Foley and Julie Thao, written communication, December 13, 2008).

To create and sustain a culture of safety, an organization must first recognize the value of teamwork in each patient’s unique situation. In this culture, the goal must always focus on the patient, and keeping the patient safe from medical harm must be just as important as treating the illness or disease. Listening to patients, families, and advocates must not only be tolerated, but also welcomed and endorsed by all levels of management (Jennifer Dingman, written communication, December 13, 2008). To continually improve, teamwork training, human factors, and interventions need to be refreshed constantly by organizations, with input from patients who have received care at the organization. It makes the training real and applicable to the participants. It is also important to have input
on team training from patients to put the patient and family at the center of team improvement.

Everyone, including patient advocates and patient safety experts, is gradually realizing that leadership within organizations—and not just at the senior executive levels—is a critical ingredient to safer health care. In the words of Dr David Hunt, Chief Medical Officer for the Office of the National Coordinator for Health Information Technology with the US Department of Health and Human Services, “Most important to safety practice adoption are leadership, resources, and systems” (oral communication, December 13, 2008). Engaged organizational leadership is then able to apply financial and talent resources through systematic processes and accountability.

Safe, high-quality health care is neither accidental nor static. Rather, it is the result of deliberate actions by dedicated people—continuous actions, including active listening, planning, implementation, and evaluation by organizational leaders and providers of care within their health care enterprise. The most important aspect of such systems and actions is communication. Active listening by leaders and providers, to each other and to patients and families, is a dynamic communication process that is critical to the accurate assessment, diagnosis, and treatment of patients. It is also important for generating a meaningful culture of safety that fosters the prevention of medical errors. Listening and responding to the immediate and emerging concerns and complaints of patients and families, 24/7, from admission to discharge, throughout the continuum of care, as well as analyzing the occurrence of a harmful error, are indispensable components—the sixth vital sign—of safe, responsible, and ethical health care practice (Patti O’Regan, written communication, December 13, 2008). Such approaches must be fostered by leadership and supported by appropriate organizational structures, processes, and systems.

It is critical for caregivers to listen to patients and their families. They must anticipate breakdowns in information transfer. The patient’s symptoms and expressed concerns should be acknowledged, documented, and directed appropriately as the patient navigates the complexities of the health care system. That information, along with the patient’s diagnosis, needs to follow the patient through his or her follow-up care as well. For example, critical laboratory values and test results must be effectively communicated in a timely manner. Failing to do so puts all at risk—the facility, the staff, and especially the patient. It is important to tighten the links in the chain (Becky Martins, written communication, December 13, 2008).

Active involvement of patients and families in health care organizations by formally incorporating their input into leadership structures, committees, and systems is rapidly evolving across the country. Much potential can be realized by the formation of Patient and Family Advisory Committees; however, these partnerships should not be limited by merely considering them as simple content review groups. The engagement of patients and families can be much more than token engagement, and success revolves around their having a clear mission and vision with expectations and of members, so that the activities from this type of initiative may be sustained. (Farris Timimi, MD, Cardiovascular Diseases, Mayo Clinic Rochester, written communication, November 23, 2009).

Leading-edge organizations, such as the Dana-Farber Cancer Institute, have built patient and family input and accountability into almost every area of functionality. They have addressed this area with great impact and with no increase in malpractice risk (James Conway, oral communication, December 10, 2007). It is critical that leaders also look outside their own organizations and learn not only from tragic events and near misses, but also from other organizations on how to develop rapid response teams to reduce the risks to children and adults in their care. Putting the systems in place to learn from other organizations is the responsibility of leaders. Not allowing patients to be harmed from clearly publicized risks is the direct responsibility of health care leaders (Dennis Quaid, written communication, November 22, 2009).

Leaders drive values, values drive behaviors, and behaviors drive performance. Engaged leaders need to provide the resources necessary to ensure that the systems are in place to guarantee that vital patient and family input are built into the practices adopted. Leadership, resources, and systems—these 3 elements are critical to success.

**BRIDGING HEALTHCARE SILOS**

Integration of the silos of risk management and performance improvement may be one of the most difficult tasks an organization must undertake. Patient safety experts and advocates recommend that patients and family members be (1) involved in planning for and establishing guidelines for mitigating patient safety risks and hazards; (2) forewarned about safety risks and hazards when entering the hospital; and (3) listened to when they observe risks and hazards while in the hospital. This should all be done in a practical and helpful manner (Dan Ford, written communication, November 7, 2008).

Patients must be given full details of all treatment, procedures, and medication adverse effects by their providers in easy-to-understand terms. Risks and benefits must always be discussed, with provider recommendations offered as suggestions, not demands. Patient and family wishes must always be respected, and everything possible must be done by providers to honor the wishes of the patient and family. When errors do occur, honesty and efforts to find the root cause of the issue must be addressed and followed up in order for this culture to sustain (Jennifer Dingman, written communication, December 13, 2008). Progressive organizations, such as the University of Illinois and the University of Michigan, provide role models for apology and disclosure strategies that all organizations can readily follow.

The inclusion of patients and families on patient safety and performance improvement committees that address the areas targeted by these practices should be strongly recommended or required. The closer patients and families are to the planning for preventing adverse events, the more patients and family members will feel vested in this process. Patients and family members are not necessarily clinical experts, but they do have ideas to share, along with eyes and ears for observing (Dan Ford, written communication, November 7, 2008).

Some patients do not seek care because of fear. Health care providers can improve their patients’ acceptance of their diseases or conditions through listening to their concerns and educating the patients about their choices. What may seem routine to caregivers can be overwhelming to patients. Listening, reassurance, and education are keys to a healthy patient (Arlene Salamendra, written communication, October 1, 2009). The use of multimedia tools and techniques must be considered to optimize the recognition of health literacy gaps and to ensure consistent, reliable message delivery and assimilation.

Nondisclosure of medical errors has been described in an article by Sue Sheridan and other patient safety advocate experts:
"It is so hard to articulate the profound sense of betrayal and abandonment that my family felt. I can only describe it as a hit-and-run health care accident. My family was abandoned at the side of the road, injured and traumatized by a well meaning motorist who fled because of legal and personal fears. We were left to seek out help on our own with our own resources. No one looked back.

They pretended as if nothing had happened, including those eyewitnesses on the side of the road. A hit-and-run, in our world, is considered criminal. Why is it OK in medicine? The nondisclosure of medical error is the most destructive phenomenon in health care. Trust and confidence disappears in a heartbeat."

Involving patients and families in improving nursing care is vital to performance improvement. For example, input from patients should be sought to help caregivers put systems in place to provide both the patient and family with an understanding of how nursing care is delivered in a particular unit, including what to expect from nursing care, each hour, each shift, and every day; who is in charge; and how to get help. Information on whom the patient or family should go to with a problem, concern, or complaint should also be provided. Caregivers must listen to patient and family feedback about the effects that short-staffed nursing shifts had on their care, and incorporate that feedback into strategies for improvement and action plans (Mary Foley and Julie Thao, written communication, December 13, 2008).

Nurses are not the only caregivers who are vital to patient safety and the patient’s experience. Staff members, such as respiratory technologists, radiology personnel, and clinical pharmacy personnel, are subject to the same issues that nursing staff faces. Staffing matters must be addressed by the management to sustain a culture of patient safety. Caregiver staffing levels must always be reasonable, allowing the caregivers to spend adequate time providing patient care, completing paperwork, and performing other duties. Cuts must never be made in these areas because of the critical need for safe inpatient care. Input from patients and families to committees that are examining risks pertaining to workforce issues is vital, as is input on patient education (Jennifer Dingman, written communication, December 13, 2008).

Delayed diagnosis and treatment, as well as communication breakdowns that may harm patients, can be much improved by reengineering discharge programs that include procedures incorporating these practices. Until all information about care is in digital form, and patients and families are no longer required to be part of the information transfer process, ongoing work is needed on the transmission of information to and through patients and families. One example opportunity for improvement exists at the interface between acute care hospitals and nursing homes. Discharges to nursing homes, first-time admissions to hospitals from nursing homes, and especially readmissions to hospitals from nursing homes provide ample opportunity for the coordination of information transfer that can greatly reduce suffering, harm, stress to families, and cost.

As organizations treat an aging population, communication about life-sustaining treatments must be constantly improved. This is not possible without patient and family input. Fully honest, complete, transparent, and early disclosure to the patient and the family that imparts the clear and realistic risks, benefits, expectations, and potential for improvement offered by all possible life-sustaining treatments is important, followed by a full assessment for complete understanding (Mary Foley and Julie Thao, written communication, December 13, 2008).

FOCUS ON EXAMPLE COMPONENTS

There are 2 specific areas of clinical care that are particularly relevant for patients and families—health care-associated infection and medication management. Health care-associated infections are a highly visible aspect of contemporary health care. They are also a component for which patient advocates have 2 main recommendations. The first is that, because the role of patients and visitors is critical to the prevention of health care-associated infections, the awareness of patients and visitors must be raised to ensure that they understand the seriousness of the processes that can affect health care-associated infections. For instance, high-contact surfaces that patients and families touch frequently, such as TV remote controls and pulse oximeters in hospitals, pose real risks and great new opportunities for low-cost interventions to reduce exposure to pathogens (Dr Robert Cima, Colon and Rectal Surgery, Mayo Clinic, written communication, November 18, 2009). The caregiver organization should encourage partnership with patients and families to improve the reliability of those processes (Becky Martins, written communication, December 13, 2007).

The second is that education should be provided to the patient and the family to address their concerns. Hospital leadership should promote cleanliness not only among staff but also among visiting family, by actively engaging patients and family in education on infection control. This is accomplished by emphasizing the spirit of teamwork between the staff and family. Partnership among caregivers, patient, and family could be emphasized. Patients and families should be provided a place to go with their concerns about lack of hand hygiene or other infection-related issues (Mary Foley and Julie Thao, written communication, December 13, 2008).

The medication management and delivery systems (with their subset processes) are relatively well understood, compared with other areas of health care. One particular area of concern, however, is the issue of medication reconciliation, and here, the roles of patients is crucial. Patients often have a good understanding and knowledge of their own bodies and medications. If they do not, caregivers need to know about it. Regular and consistent patient and family input to processes of medication reconciliation is vital to full systems improvement (Dan Ford, written communication, December 13, 2008). Accuracy and consistency of medications are crucial for the successful treatment of illness and disease states with medications and their inherent complexities.

Good leadership of pharmacy delivery services requires input from all stakeholders. Patients and families are crucial to reducing medication errors, not only through learning to use medications properly, but also to provide suggestions to pharmacists and other caregivers about the patient’s and family’s
roles in the system. They have a vested interest in the process and can be attuned to detect even the slightest details that may be out of place or that do not seem right. Systems need to be put into place to ensure that providers are reminded to be sensitive and responsive to questions asked by patients and family members. Listening is crucial (Dan Ford, written communication, November 7, 2008).

A FUTURE WITH PATIENTS AND FAMILIES
Patient and family involvement starts with educating patients and families and ends with listening to them and taking them seriously. If patient and family input is emphatically built into systems of performance improvement, and if patients and families are taken seriously, as real experts, and are respected for their valuable perspectives on how care can be improved, then organizations can improve at improving. They can then begin to know patients and families better, love them better, and make it easier for them to move through health care organizations (Moose Millard, oral communication, August 1, 2006).

Resources in health care are in short supply, yet the resources of patient and family help and time are almost limitless, are ready to be tapped, and can have a huge impact on improving the reliability and overall success for any organization.

ACKNOWLEDGMENTS
We wish to recognize the following patient advocates for their overall commitment to improvements in patient safety. Without the tireless work and unshakeable commitments of these individuals, and others like them, such as the patient advocate authors of this article, the movement for improved patient safety and quality in health care would not be experiencing the momentum that it currently enjoys. Thanks to these individuals, and the millions of patients and family members they represent, health care is indeed improving and the future direction of health care is clearly benefiting from this sea-change of influence.

Nancy Conrad: Founder, Community Emergency Healthcare Initiative; Founder, Conrad Foundation
Moose Millard: Texas Medical Institute of Technology Culture and Teamwork Task Force member; former Chief Pilot, Southwest Airlines
Dennis Quaid: Actor, International Patient Safety Champion
Julie Thao, RNC: Patient Safety Fellow, Texas Medical Institute of Technology

REFERENCES
March 4, 2010

Dear Healthcare Leader:

We are delighted to announce that the Journal of Patient Safety has graciously given us permission to distribute copies of recently published articles to you in the interest of helping you adopt the National Quality Forum Safe Practices for Better Healthcare – 2009 Update and 2010 Update.

The Journal of Patient Safety is dedicated to presenting research advances and field applications in every area of patient safety and we give our highest recommendation for them as a valuable resource toward patient safety from hospital bedside to boardroom. It is in the fulfillment of this mission that they make the gift of these articles to you in your pursuit of your quality journey.

The home page of the Journal of Patient Safety can be accessed at the following link: http://www.journalpatientsafety.com and subscription information can be directly accessed online at: http://www.lww.com/product/?1549-8417.

We want to acknowledge you and your institution for your current efforts in patient safety. We hope you enjoy this article and find it useful in your future work.

Sincerely,

Charles R. Denham, M.D.
Chairman