

Busting the Myths about Engaging Patients and Families in Patient Safety



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Health care organizations are increasingly creating systems and processes to make their organizations safer and more highly reliable. Today, most health care organizations commonly use technology to aid decision-making, along with process improvement tools and methods such as Lean and Six Sigma to identify and target breakdowns in care. Safety strategies also are now a key component of professional education. The role that patients play in health care safety and reliability, however, is less defined.

That is not to say that patients are not aware of the hazards inherent in health care. There is widespread agreement that avoidable errors are far too common in health care and contribute to patient harm far too often. Patient safety groups and health care organizations regularly provide education that encourages patients to ask questions and speak up about their safety concerns.

Although there is a growing movement toward patient-and family-centered care that encourages partnerships with patients as a way to improve care and reduce costs, barriers to patient engagement still exist. When communicating routine health-related information to patients and families, health professionals must adhere to a myriad of federal and state laws and regulations. Further, when communicating information associated with a possible adverse event, there are additional considerations from a medical-legal perspective. However, there also are several common myths or misperceptions about sharing health information that also can create an unnecessary impediment to full, candid and transparent communication. For example, one hurdle is that health care professionals may think they can't open up a dialogue with patients and families over concerns that conversations will be misinterpreted.

"Busting the Myths about Engaging Patients and Families in Patient Safety" is being issued as a resource by The Joint Commission, with input from its Patient and Family Advisory Council, as a way to explore these perceived obstacles and encourage health care professionals to engage in open dialogue with patients. Nurses, physicians, pharmacists, clinical therapists, social workers and other health care professionals who actively seek to engage patients and their families are leading the way in creating healing partnerships. These partnerships embrace the expertise of health professionals and the strengths of patients and families.

What Is Patient Engagement?

Before considering the myths and facts that surround engaging patients and families in safety efforts, what exactly is patient engagement? One definition is: “patients, families and their representatives, and health professionals working in active partnership at various levels across the health system – direct care, organizational design, governance and policy making – to improve health and health care” (Health Affairs, February 2013, vol. 32 no. 2 223-231: <http://content.healthaffairs.org/content/32/2/223.abstract>). This definition recognizes that engagement is a dynamic process that encompasses many activities. In order to be engaged, patients need to have the mindset to participate in their care, knowledge about health and the health system, and the skills to ask questions and make informed decisions (Center for Advancing Health, *Here to stay: What health care leaders say about patient engagement*).

Helping patients and families become more engaged in their health care presents many challenges for health care organizations and health care professionals. Some of the challenges involve overcoming conscious or unconscious perceptions that create barriers between patients and providers. Overcoming these barriers is not easy, but it is essential in order to create the kind of safe, high-quality health care experiences that both providers and patients want. Next time there’s hesitation about talking with patients and families about safety, health care providers can consider whether the following myths may be causing their reluctance to having those conversations.

Health Affairs, February 2013, vol. 32 no. 2 223-231: Retrieved from <http://content.healthaffairs.org/content/32/2/223.abstract>

Center for Advancing Health. (2014). *Here to stay: What health care leaders say about patient engagement*. Retrieved from http://www.cfah.org/pdfs/here_to_stay_2014.pdf?utm_source=CFAH+Digest+7.1.14&utm_campaign=CFAH+Digest+7.1.14&utm_medium=email.

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Myth #1: Communication is important to quality and safety, but HIPAA (Health Insurance Portability and Accountability Act) regulations and other privacy rules don't let us talk openly with patients and families.



Facts: A federal law designed to safeguard sensitive health information, the HIPAA Privacy and Security regulations (HIPAA) are often a source of confusion when it comes to communication. While HIPAA requires health care organizations to provide certain protections for patient information, it is actually quite flexible (Health & Human Services, Office of Civil Rights, *Safeguards*). The bottom line is that HIPAA provides privacy protections, while also allowing for disclosing information that is necessary in order to deliver care. Rather than thinking of HIPAA in terms of what can't be shared, consider what is allowed under HIPAA regulations:

- **Communication with a patient's family members or friends** – Health care providers can share and discuss health information with family, friends or other individuals who are directly involved in a patient's care (HHS, Office of Civil Rights, *Sharing health information with family members and friends*). The law allows sharing information when the patient either agrees or if present in the room with the patient, the patient does not object. For example, providers can talk to a patient about his or her condition when a family member or friend is present at the patient's request. Information about a patient's needs also can be shared with a health aide, interpreter, or person driving a patient. In some situations, HIPAA also allows health care professionals to use their own judgment about whether the patient wants health information discussed in front of family members, friends, or other individuals involved in a patient's care (HHS, Office of Civil Rights, *Sharing health information with family members and friends*). If a patient specifically asks a provider not to share information with an individual, then that decision must be respected. (HHS, Office of Civil Rights, *Sharing health information with family members and friends*).

It's also worth noting that written permission from a patient or some other form of documentation is not required under HIPAA in order to communicate with family, friends, or other individuals who are directly involved in a patient's care. Health care organizations often make their own rules about documentation in these circumstances in order to be able to maintain a record of the patient's permission, but the law does not require this. (HHS, Office of Civil Rights, *Safeguards*).

- **Sharing information when a patient is not present or cannot give permission** – In an emergency, providers can use their own judgment in deciding whether to communicate with family, friends or others when the patient is incapacitated or not present (HHS, Office of Civil Rights, *Sharing health information with family members and friends*). If a health care professional believes sharing health information is in the best interest of the patient, then he or she may do so. The key is sharing only the information that the person involved in the patient's care or payment needs. Providers also may choose to wait until the patient can agree to share information.
- **Medical records** – A patient, or his or her representative, can obtain a copy of the medical record or other health information (HHS, Office of Civil Rights, *Your health information privacy rights*). [Note: There is a cost for copying and mailing the record.]
- **Emails and phone calls** – With patient permission, HIPAA allows providers to communicate with patients by email as long as appropriate safeguards are employed (HHS, Office of Civil Rights, *Health information privacy*). In addition, and as discussed above, providers can discuss information about a patient with a patient's family members, friends or other individuals involved in their care by phone (face to face, as well as in writing) (HHS, Office of Civil Rights, *Sharing health information with family members and friends*).

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Sources for Myth #1 facts:

Health & Human Services (HHS), Office of Civil Rights. Safeguards. Retrieved <http://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/special/healthit/safeguards.pdf>

HHS, Office of Civil Rights. Your health information privacy rights. Retrieved from http://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/consumers/consumer_rights.pdf

HHS, Office of Civil Rights. Covered entities and business associates. Retrieved from <http://www.hhs.gov/hipaa/for-professionals/covered-entities/index.html>

HHS, Office of Civil Rights, Sharing health information with family members and friends, retrieved from: <http://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/consumers/sharing-family-friends.pdf>

HHS, Office of Civil Rights, Health information privacy. Retrieved from http://www.hhs.gov/ocr/privacy/hipaa/faq/health_information_technology/570.html



Myth #2: The threat of lawsuits makes straightforward conversations impossible.

Facts: One of the basic principles of patient safety is to talk with and listen to patients. When health care professionals engage patients and families in dialogue and share information, it is easier to understand patient values and preferences and arrive at decisions together. These shared deliberations result in consensus that can be thought of as a “shared mind” between patients and providers, with the resulting engagement improving patient outcomes and quality of life (Epstein et al., *Why the nation needs a policy push on patient-centered health care*).

If something does go wrong, health care professionals should have honest conversations with patients and families. However, organizations may not know all the contributing and causative factors immediately following an adverse event. Organizations should commit to keeping patients and families updated regularly as more information becomes available and facts are known. Many professional associations view disclosure as fundamental to ethical care, and The Joint Commission requires disclosure of sentinel events as part of accreditation requirements. For example, the Rights and Responsibilities of the Individual (RI) Standard RI.01.02.01, element of performance (EP) 21, requires an accredited organization to inform the patient or surrogate decision-maker about unanticipated outcomes of the care, treatment, and services that relate to sentinel events (as defined by The Joint Commission). EP 22 of that standard specifies that the licensed independent practitioner who is responsible for managing the patient’s care, treatment, and services (or his or her designee) must inform the patient about unanticipated outcomes of care, treatment, and services that relate to sentinel events when the patient is not already aware of the occurrence, or when further discussion is needed.

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Open dialogue has also been shown to reduce the likelihood of lawsuits (Epstein et al., *Why the nation needs a policy push on patient-centered health care*). Disclosing, investigating, and resolving instances when errors occur has become the norm at a number of well-known health care facilities and systems (Joerling, *Does sorry work? The power of full disclosure in the healthcare setting*). One large health system saw malpractice claims drop by 36 percent after implementing a formal process to acknowledge errors, apologize, and provide compensation, if appropriate (Kachalia et al., *Liability claims and costs before and after implementation of a medical error disclosure program*). Recent research suggests that this model of doing the right thing when things go wrong could be used nationwide to improve patient safety and reduce malpractice claims (Bell et al., *Disclosure, Apology, and Offer Programs: Stakeholders' Views of Barriers to and Strategies for Broad Implementation*). In the meantime, 36 states now make it easier to say “sorry” with laws that make apologies inadmissible in lawsuits, leading to quicker resolution of cases. (Ho, *Does sorry work?*).

Sources for Myth #2 facts:

Epstein, R. Fiscella, K., Lesser, C., & Stange, K. (2010). Why the nation needs a policy push on patient-centered health care. *Health Affairs*, 29(8), 1489–1495. Retrieved from <http://content.healthaffairs.org/content/29/8/1489.full.pdf>

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Ho, B. (2010). *Does sorry work? The impact of apology laws on medical malpractice*. Retrieved from <http://irving.vassar.edu/faculty/bh/Ho-Liu-Apologies-and-Malpractice-nov15.pdf>.

Health Privacy Project. *Myths and facts about the HIPAA privacy rule*. http://www.accessmyhealth.org/documents/HIPAA%20Myths_and_Facts.pdf

Myth #3: Patients and families either aren't interested in or able to talk about their care.

Facts: Many factors influence the willingness and ability of patients to be involved in their care. Barriers range from low health literacy to fear to provider reactions to uncertainty about how to be involved. (Agency for Healthcare Research and Quality, *Guide to Patient and Family Engagement: Environmental Scan Report*). Cultural factors, age, sex, language skills, cognitive limitations, and other issues may also make patient and family engagement difficult (Health Affairs, *Patient engagement*). Even the very culture of the American health care system, including the delivery and financing structures, may make engagement difficult (Center for Advancing Health, *Here to stay: What health care leaders say about patient engagement*). Altogether, less than half of American adults may be actively involved in managing their own health and health care (Hibbard & Cunningham, *How engaged are consumers*).

While it is true that some patients may not be able or willing to talk about their care, studies show most people do wish to be involved and informed (Fowler, *Patients want to be involved*). Involving patients in their care is also a basic tenet of health care reform, and a principle supported by private organizations such as The Joint Commission, the American Medical Association, and the American Hospital Association. Patients need to participate in all decisions about their health care because they are the center of the health care team (The Joint Commission, *Facts about Speak Up™ initiatives*). Several Joint Commission requirements in the Rights and Responsibilities of the Individual (RI) chapter of the accreditation manuals address the right of the patient to participate in decisions about their care, treatment and services, as well as the right to give or withhold informed consent (RI.01.02.01, RI.01.03.01).

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By “activating” patients through conversations, patients gain the knowledge and skills to follow treatment plans and stay healthier (Greene & Hibbard, *Why does patient activation matter?*). Patients and families who understand what they need to do to take care of themselves are also less likely to have complications or adverse events (AHRQ, *Educating patients before they leave the hospital reduces readmissions, emergency department visits and saves money*).

Using plain language and avoiding technical or medical jargon, along with including examples, stories and visuals also can help to engage patients and families (The Joint Commission, *Advancing effective communication, cultural competence, and patient- and family-centered care*). Even when patients or families don’t seem interested, it’s important to provide ongoing opportunities for questions and encourage dialogue (The Joint Commission, *Advancing effective communication, cultural competence, and patient- and family-centered care*). Shared decision-making, collaborative care planning and motivational interviewing are just some examples of ways that providers and patients can communicate together about health care. There are many free resources available online that can be used to help health care providers involve patients and families in conversations and make informed decisions about their care.

Ultimately, health care professionals who make the effort to reach patients and families by engaging in quality communication are better able to meet the health needs of their patients (AMA, *Improving Communication – Improving Care*). That’s because they build trust by sharing information that educates and empowers patients and families (AMA, *Improving Communication – Improving Care*).

Sources for Myth #3 facts:

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Agency for Healthcare Research and Quality. *Educating patients before they leave the hospital reduces readmissions, emergency department visits and saves money*. Retrieved from <http://archive.ahrq.gov/news/newsroom/press-releases/2009/red.html>

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Myth #4: Health care professionals and patients and families don't share the same views on health care quality.

Facts: Health care professionals and patients and families are aligned in seeking the best quality of care that is free from overuse, underuse or misuse — the right care for the right patient at the right time. Research shows that patients and health care providers agree on one important issue: they think the quality of care they receive or they give is generally good. Differences may arise, though, in opinions about what exactly quality care is. Patients often define quality through the lens of the personal interactions they have with providers, while health care professionals view quality as the clinical care they provide (AHRQ, Guide to Patient and Family Engagement: Environmental Scan Report). Both of these views of quality care are important.

This fundamental difference may come into play when, for example, a patient has previously had a poor experience with a health care professional or a health care facility. Or, perhaps a patient has had difficulty in the past getting access to treatment. Patients also may not be feeling their best, and their families may be under stress.

Ways providers can lay the foundation for collaborative interactions include:

- Acknowledging the perceptions of patients and families and avoiding being rude or dismissive can help providers reach patients and avoid problems (Wofford et al., 2004).
- Listening and letting patients and families know they are being heard helps to avoid feelings of mistrust and disrespect (Wofford et al., 2004). It also lets patients and families know their health care providers are available to them.
- Looking for areas of agreement during challenging situations with patients and families. For example, patients and providers both want patients to get and feel better (Gilbert, *What matters to patients and careers*). Everyone involved also can agree getting the right care from the right providers, being treated with respect and sharing information are areas of common ground (Gilbert, *What matters to patients and careers*).

Research shows that patients and health care providers agree on one important issue: they think the quality of care they receive or they give is generally good.

- Letting patients tell their story without interruption and providing affirmation for patients by showing empathy are some other strategies to help emphasize that providers and patients are on the same team (AHRQ, Guide to Patient and Family Engagement: Environmental Scan Report).

Sources for Myth #4 facts:

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Gilbert, D. (2011). What matters to patients and carers? Centre for Patient Leadership. <http://www.inhealthassociates.co.uk/the-patients-dozen-what-matters-to-patients-and-carers/>



Myth #5: There is no real payoff in engaging patients and families.

Activation helps improve patient safety and health outcomes. Education also reduces underuse or overuse of health services and reduces costs.

Facts: Health care organizations can reap many benefits from “activated” patients and families – those who have the knowledge, skills and confidence to manage their own care. Health care professionals can and should invite and encourage patients to engage fully in their care, which in turn improves patients’ experiences with care. These improved experiences are important to HCAHPS scores, which are part of the Value-Based Purchasing (VBP) program the federal government uses to calculate a hospital’s Medicare payments (HCAHPS, *Fact sheet*), and in efforts to attract both patients and staff.

Activation helps improve patient safety and health outcomes (Hibbard & Greene, *What the evidence shows*). Education also reduces underuse or overuse of health services and reduces costs. From preventing falls to reducing readmissions to controlling diabetes, helping patients understand and know how to manage their conditions leads to better quality of life (Center for Transforming Healthcare, *Preventing falls with injury project*; Robert Wood Johnson Foundation, *Heart failure education reduces readmissions*; Medscape Medical News, *Diabetes improves with behavioral, educational interventions*).

In addition to promoting greater patient involvement in their own care, organizations can improve care processes and patient satisfaction by involving former patients, family members and patient advocacy groups in various committees, councils and task forces within the health care system. The Affordable Care Act (ACA) also makes clear connections between quality, engagement with patients and families, and reimbursement. For example, a patient representative must serve on the governing board of an Accountable Care Organization (ACO).

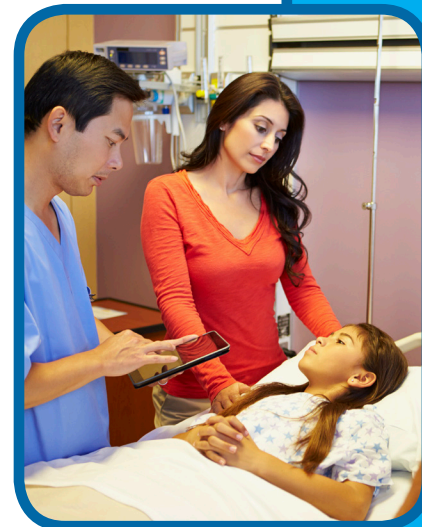
Below are two examples of positive results yielded from partnering with patients and families:

- One hospital that began involving patients and families in safety efforts after a highly publicized preventable death saw a culture shift that improved medication reconciliation and eliminated fatal medication errors during a 10-year period (Johnson & Abraham; Reinersten et al., 2008).
- A health system that began seeking input from patients and families decreased nurse turnover from 15 percent to 5 percent in three years and improved patient, staff and physician satisfaction (Johnson & Abraham).

The flip side of not investing in patient and family education also is worth considering:

- Hospital costs and reimbursement are directly affected when patients are not involved in their care (Hibbard et al., *Do increases in patient activation result in improved self-management behaviors?* Hibbard & Green, *What the evidence shows*). For example, failed communication between health care professionals and patients and families is the most common cause of malpractice suits, which drive up costs (Eastaugh, *Reducing litigation costs through better patient communication*).
- Complaints, which take time and money to investigate and track, also are tied closely to communication and education. Disrespect, disagreements about expectations of care, inadequate information, and distrust are common reasons that patients lodge complaints (Wofford et al., *Patient complaints about physician behaviors*).

The bottom line is the investment in creating partnerships with patients and families makes sense for health care organizations, health care professionals and patients. To quantify exactly how engagement – for example, through a patient and family advisory council – benefits an organization, develop metrics for pre-and post-implementation, implement all projects with defined processes, and track all projects and results.



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