

Disclosure of Unanticipated Events in 2013

Prologue to the Re-Release of the Three ASHRM Disclosure Monographs

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Those who cannot remember the past are condemned to repeat it.

George Santayana (1863-1952)

Healthcare Risk Managers live in a unique world of being perceived as leaders (AIG, 2013) and periodic public scrutiny. (Elliott, 2013) (Zur, 2010) As reflected in the ASHRM vision, we see our role as advocates for safe and trusted healthcare. We recognize that an effect of appropriate care safely delivered is financial savings to the organizations we serve. Taking the enterprise view, Risk Managers also know that unanticipated patient events affect not only the clinical areas of our organizations, but our staff, our reputation, and our financial resources to provide services, in essence our entire organizational (enterprise) health.

A key factor in our ability to move towards safer and trusted healthcare has been the recognition that error and failure are part of the human condition and must be addressed through identification and transparency (Institute of Medicine, 1999). In 2001, supporting the recognition of patients' right to autonomy to direct their healthcare and be informed about their own health the Joint Commission (then known as the Joint Commission on Accreditation of Healthcare Organizations) included in their then new Patient Safety Standards, a standard that patients would be informed about unanticipated outcomes of their care.

The novel idea of mandated disclosure raised many questions. For while some people believed in open communication, there were many who were concerned about the ramifications. And, of course, in a world of litigation there were the legal implications. How would patients and families react? Would they lose hope in their care? Would they lose trust in the system and thereby affect their healing? Would they become angry and sue?

Making the change to more open communication was even more difficult because the evidence supporting it was not extensive in the literature in 2001. The time from an event to the resolution of a traditional medical malpractice suit can be many years, meaning that the impact of disclosure on litigation wouldn't begin to be fully realized until it was a common practice among most, if not all, healthcare providers for at least 10 years. Nonetheless, the first unpublished (and now published) data in support of disclosure began to emerge from early adopters such as the Lexington, KY VA (Kellogg, 2007), University of Michigan (Masson, 2010) (Boothman & Hoyler, 2013), and Copic (Lembitz, 2013). In a balance of information, skeptics alleged that true disclosure of all unanticipated events would be detrimental and could possibly bankrupt the system (David Studdert, 2007).

ASHRM, in its desire to achieve its mission, determined to look at the rationale and best practices for disclosure. Consequently, in 2001, ASHRM released its first Monograph on Disclosure, laying the groundwork for future activity, and in 2003, ASHRM released a series of three monographs on Disclosure:

Monograph 1 – Disclosure of unanticipated events– the next step in better communication

Monograph 2 – Creating an effective patient communication policy

Monograph 3 - Disclosure: What works now and what can work even better

After a recent article that decried Risk Managers as inhibitors of transparent care (Elliott, 2013), ASHRM resurrected the 2003 Monographs with the question: Are these as relevant today as they were ten years ago? Do risk managers support a culture of transparency? A group of us reviewed these monographs, and the answer is a resounding “yes!”

While the monographs are attached in their original entirety, the decision was made to provide a prologue with an update. The questions to be answered are:

What Has Changed since 2001 in Disclosure Practices?

What Remains the Same since 2001 in Disclosure Practices?

What Have We Really Learned in Thirteen Years?

The answers to these questions with the accompanying monographs, presents a perspective that will allow the Risk Manager and the concerned organization to approach open communication with an understanding of the power of disclosure, a framework for developing appropriate policies and procedures that will support the effort, and a template for teaching the skill of humane disclosure.

What Has Changed since 2001 in Disclosure Practices?

Very little has substantively changed since 2001.

- Many more states have apology laws. In 2003, 4 states had benevolent gesture statutes. At the time of this re-release, 36 states have “apology laws” of one sort or another (States with Apology Laws, 2013)
- The true psychological and even psycho-physical effects of being the provider or caregiver involved in an unanticipated event has been recognized. While our focus remains on the patient and family, the needs of those who unintentionally are party to the event cannot be ignored. Some healthcare organizations are beginning to develop methods of supporting and caring for providers and others who have either been at the sharp end, or peripherally involved in the event . Organizations such as Medically Induced Trauma Support Services (MITSS) have developed toolkits to help healthcare organizations develop services that address the needs of all parties involved in an event (Tools for Building a Clinician and Staff Support Program, 1210).
- The evidence is being published showing that transparency and appropriate apology win trust and can reduce costs (Masson, 2010) (Boothman & Hoyler, 2013) (Kellogg, 2007), (Lembitz, 2013) (Modern Healthcare, 2013) and yet there remains debate (Giordana & O'Grady, 2013).
- The Joint Commission on Accreditation of Healthcare Organizations is now simply the Joint Commission.

What Remains the Same since 2001 in Disclosure Practices?

- There are still legal considerations. Depending upon the jurisdiction in which the healthcare organization operates, there could be legal restrictions on how much you are allowed to tell the patient about outcomes of investigation without jeopardizing the protection of healthcare workers to speak candidly during the investigative process. This can have a chilling effect on the willingness of staff to help solve problems and remediate latent unsafe situations. There may also be rules about reporting practitioners involved in medical errors to professional licensure boards which can instill fear about participating in a disclosure discussion. These are still real considerations when coaching providers about honest communication, and when answering questions. Unfortunately, not all statutes yet make it easy.
- Disclosure remains difficult. There are many reasons for this, but one of the most basic is that as humans working in healthcare, we fundamentally don't want to hurt others.

When we do, we are shaken to our professional and human essence. Because of that we feel a cognitive dissonance with the unintended outcome, and a blow to our professional desire to do well (Banja, 2005). This is unlikely to change. What can change is familiarity with having difficult conversations. This can be accomplished through training and practice. Just as organizations practice clinical responses to emergent situations that happen infrequently, our organizations need to build both initial and ongoing practice of difficult discussions including the possibility for apology.

- Appropriate apology remains difficult. In the early years of the disclosure and transparency movement, there were some who believed that apology should be offered immediately, always and often. It became apparent that there are limitations and considerations for apology. The work of people like Aaron Lazare and Lee Taft helped elucidate that apology is healing when heartfelt and appropriate, potentially inappropriate when it's premature, and can be divisive when it's not genuine (Lazare, 2005) (Taft, 2000). Efforts to understand apology and use it appropriately, humanly, and authentically will continue to be difficult, but hopefully less so as it becomes part of our culture.

What Have We Learned in Thirteen Years of Open Communication and Disclosure? And what is the next frontier for the Cultural Shift towards open communication?

- Transparency, open communication and disclosure are part of a continuum of communication. Disclosure is not a unique, discrete form of communication, but part of a way to approach patients, families, and our healthcare staff. Disclosure, in its simplest form, is no different from any other type of difficult conversation held in the healthcare organization. Providers' daily offer difficult alternatives to patients during consent, deliver terminal prognosis to patients they have known for years, children are disconnected from artificial life support, and we tell families information they don't want to hear. Daily we talk with staff about difficult work situations. What makes disclosure so very different is the sense of vulnerability.
- To increase the willingness of providers to disclose, the culture must shift to support provider and staff human-ness. Early on this journey to transparency, physicians in some settings would state that they feared Risk Management and others punishing them if they admitted to error. Although Risk Managers may believe that this was never true, or if it once was, and it is no longer true, it takes longer for those who are observing to notice the change. Disclosure will become part of the fabric of healthcare when healthcare organizations demonstrate complete concern for all parties involved in an unanticipated event.
- Disclosure is a process and not an event. While an initial disclosure may remain the most difficult from both a communication skill, human vulnerability, and liability

perspective, an initial disclosure is not the only conversation that should occur after any unanticipated event. In the early years, providers would sometimes state, “I disclosed. What else is needed?” With the maturing of our experience and drawing on psychology, we know that people need to hear news several times for it to truly sink in. Furthermore, we need to go back with information we may gather after further investigation, with possible offers of restitution and apology when appropriate. Healthcare organizations need to take care to ensure that providers and staff are not lulled into the notion of a single disclosure, but understand that the process will be supported by the Risk Manager and others in the organization.

- Most state apology laws are, in essence, empathy laws. They protect providers who empathize with the patient’s situation, but not providers who admit an error. In this culture, apology will always be difficult not only because of the personal vulnerability, but also because of language. American English uses the same two words to express sympathy (I’m sorry your friend died); empathy (I’m sorry you are having to go for more tests.) and apology (I’m sorry I gave you the incorrect medication.) Given that, and the human tendency to hear what psychologically desire, any expression of empathy may be mis-heard as apology, even when inappropriate. Healthcare organizations need to be proactive in educating staff about apology. It’s power to heal. When it is appropriate. How to express empathy genuinely. And how to deliver genuine, heartfelt apology. It is not to be assumed that all humans have learned how to apologize.
- Lawsuits will still exist. There will always be individuals who are inclined to sue because of cultural, psychosocial or learned ways of dealing with conflict (Gallegos, 2013). There are also legitimate needs for compensation. It is not the goal of disclosure to prevent lawsuits. Hopefully, lawsuits that emerge after sincere efforts to communicate fully will have a different course because the need for drawn out discovery processes and determination of fault will be obviated to some extent.

In thirteen years, the most important stride forward has been to dispel the myth of Disclosure - the notion of disclosure as a “new” thing that reduces cost. Disclosure is not now, and never will be, a risk management technique. Disclosure is not intended to stop people from suing, or requesting compensation.

Disclosure honors the patient’s right to autonomy to make decisions about care. If the care situation is unclear or not known, appropriate decisions cannot be made. Sometimes those decisions may include seeking appropriate compensation. That is the patient’s right.

Disclosure is also the only path to obtaining, maintaining, or regaining patient and family trust. Disclosure will not do that by itself. However, disclosure reinforced by good faith efforts to share what is learned and to show genuine compassion for the needs of patients and families

will demonstrate that we live up our values and care about those we serve. Reduction in costs to the organization is simply a potential effect of being more trustworthy partners in care.

Healthcare organizations must give up any expectations about the outcome of disclosure as a cost savings method. That puts the emphasis on the potential effect, and not on the real purpose of the discussion. In those situations where the patient pursues litigation despite best efforts, the organization must reframe the thought that disclosure has failed. Efforts to maintain or regain trust are never a failure. The unintended consequences of building the team's strength in open communication, growing the staff's trust that the organization will support their efforts to be open, and showing good faith effort with the community we serve will always be there. Healthcare organizations that have expectations about the outcomes of disclosure discussions will be disappointed.

Disclosure is not a Risk Management technique. It is a communication tool. When done with skill, genuineness, and follow up, it is a tool towards safe and trusted healthcare.

From Geri:

On a personal note: I was privileged to be your president in 2001 when ASHRM began the journey to lead the field towards transparent, open communication with patients and families. We recognized that there are always risks when not everyone is willing or able to chance the trade-off of transparency for potential negative financial and reputational harm. In fact, some of our brave colleagues ventured into the field of open disclosure only to be taken advantage of by the press or opportunistic and angry individuals. This has not made disclosure wrong. I was also privileged to be the chair of the committee that wrote the three monograph series. Reading them again to prepare for writing this piece, I was pleased to see that ASHRM was ahead of its time in 2003, espousing ideas that would not come to be accepted for a number of years to come. Today, as we re-release these monographs with the changes noted in the piece above, I am still proud to be a part of an organization that recognizes that if we serve our communities and the patients with openness, honesty, and trust, they will respond with trust to the extent they are able. If we ask them to help us ensure that we can provide the best care possible, most people will walk that path with us. And if we base our interactions with our colleagues, patients, families and communities on striving for accountable, open communication we have a true shot at achieving safe and trusted healthcare.

Works Cited

- AIG. (2013, April 19). *AIG Study Shows Hospital C-Suite and Risk Managers Struggle with Maintaining Patient Safety*. Retrieved June 13, 2013, from Yahoo! Finance News: finance.yahoo.com/news/aig-study-shows-hospital-c-150000694.html
- Banja, J. D. (2005). *Medical Errors and Medical Narcissism*. Sudbury, MA: Jones and Bartlett Publishers.
- Boothman, R., & Hoyler, M. (2013, March 2). *The University of Michigan's Early Disclosure and offer Program*. Retrieved June 6, 2013, from Bulletin of the American College of Surgeons: www.bulletin.facs.org/2013/03/michigans-early-disclosure
- David Studdert, M. M. (2007). Disclosure of Medical Injury to Patients: An Improbably Risk Management Strategy. *Health Affairs* , 215-226.
- Elliott, C. (2013, May 30). *Bring medical misdeeds into the light*. Retrieved June 5, 2013, from CNN.com: www.cnn.com/2013/05/30/opinion/elliott-health-care-risk-management/index.html?iref=allsearch
- Gallegos, A. (2013, February 4). *How doctors can spot patients likely to sue*. Retrieved June 11, 2013, from American Medical News: www.amednews.com/article/20130204/profession/13020992/4/
- Giordana, K., & O'Grady, J. (2013, March 28). *Apology and Disclosure Programs: Should they Play a Role in Obstetrical Practice?* Retrieved June 11, 2013, from ObGyn.net: hcp.obgyn.net/malpractice/content/article/1760982/2134815
- Hall, C. (2010, June 12). *Ethics consultant is a master of apologies*. Retrieved June 11, 2013, from Dallas News: www.dallasnews.com/business/columnists/cherl-hall/20100612-Ethics-consultant-is-a-master-of-4304.3c3
- Institute of Medicine. (1999). *To Err is Human*. Washington, D.C.: The National Academies Press.
- Kellogg, S. (2007, June). *The Arty and Power of the Apology*. Retrieved June 6, 2013, from DC Bar: www.dcbbar.org/for_lawyers/resource/publications/washington_lawyer/june_2007/spology.cfm
- Lazare, A. (2005). *On Apology*. New York: Oxford.
- Lembitz, A. (2013, June). *Disclosure and early reimbursement can deter medical liability lawsuits*. Retrieved June 6, 2013, from American Academy of Orthopaedic Surgeons: www.aaos.org/news/aaosnow/sep10/managing7.asp

Masson, M. (2010, August 16). *U-M's efforts to encourage disclosure of medical errors decreased claims*. Retrieved June 6, 2013, from UMHS Newsroom: www2.med.umich.edu/prmc/media/newsroom/details.cfm?ID=1684

Modern Healthcare. (2013, February 8). *Disclosure of Medical Errors Found Effective*. Retrieved June 11, 2013, from ASQ: ASQ.org/qualitynews/qnt/execute/displaySetup?newsID=15362

States with Apology Laws. (2013). Retrieved June 10, 2013, from Sorry Works! Making Disclosure A Reality for Healthcare Organizations: www.sorryworks.net/apology-laws-cms-143

Taft, L. (2000). Apology Subverted: The Commodification of Apology. *Yale Law Journal* , 1135.

Tools for Building a Clinician and Staff Support Program. (1210, December). Retrieved June 12, 2013, from MITSS Tools: www.mitsstools.org/tool-kit-for-staff-support-for-healthcare-organizations.html

Zur, O. (2010). *The Risky Business of Risk Management - How Risk Management Guidelines Can Increase Risk and Decrease Clinical Effectiveness*. Retrieved June 12, 2013, from Zur Insitute: Innovative Resources & Online Continuing Education: www.zurinstitute.com/riskmanagement.html



Monograph

Disclosure

of unanticipated events:

the next step in

better communication

first of three parts

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FOREWORD

Because determining the value of disclosure of unanticipated medical outcomes is an evolving process in health care, ASHRM is offering this three-part monograph series on communication and disclosure.

A continuum of implementation and acceptance within healthcare organizations exists since the July 2001 definition of Patient Safety Standards by the Joint Commission on Accreditation of Health Care Organizations. This series of papers is intended to provide a “state of play” of the role of disclosure in healthcare. Models and descriptions are not intended to be prescriptive. Rather, they should serve to update the reader on ways that disclosure is being used in healthcare and prompt readers to consider if any of the strategies described herein could be helpful in their own organization.

This paper is not a description of the legal considerations a risk manager must bear in mind when implementing a disclosure practice. While some research has been done on the impact of disclosure on litigation, evidence regarding the ultimate impact of disclosure is inconclusive. As such, risk management must not ignore the legal dimensions of developing and implementing communication processes. (*Legal considerations of disclosure were addressed in the ASHRM whitepaper titled “Perspective on Disclosure of Unanticipated Outcome Information” released in July 2001. To read the paper, visit www.asbrm.org.*)

In its entirety, this three-part series will provide the current perspectives of those working on the front lines of disclosure development and deployment.

The first paper addresses:

- Initial impact of Patient Safety Standards established by the Joint Commission
- Psychological and legal barriers to disclosure and open communication
- Models used by organizations to support and influence communication
- Experiences in disclosure since implementation of the Standards, including analyses of how communication worked well – or didn’t – in some disclosure efforts.

The second paper, “**Disclosure policies: analysis of the influence of disclosure on litigation,**” will cover disclosure policies. It will provide models, discussions of strengths, and suggestions for building an effective policy. It also will present the findings on the effect of disclosure on litigation and claims activity. Finally, it will discuss the implications of disclosure in different care settings: acute, long term and pediatric.

The third paper, “**Effective disclosure: what works now, what can work better,**” will focus on techniques to improve effective disclosure and how they can be applied. In addition, this monograph will analyze different disclosure situations, providing discussion on the issues to consider and the techniques that will enhance the potential for effective communication with patients and families.

INTRODUCTION

In facing the issue of disclosure, healthcare organizations and their people need to understand and evaluate the history of disclosure in medicine as well as specific issues in the organization if they are to develop infrastructures to support truthful communication with patients and families.

When caregivers learn that an unexpected outcome arises, a risk management issue occurs. What ought to be told, and to whom? This issue must be faced whether these differences are positive or negative. Patients must know of any variance in their care to make decisions for future care or action, including seeking *legitimate* compensation for actual losses.

Patient Safety Standards and disclosure as a communication issue

The release of the Joint Commission Patient Safety Standards in July 2001 resulted in a great deal of activity and discussion on the topic of disclosure. Essentially, in RI.1.2.2, the Joint Commission mandates that patients are entitled to be informed of unanticipated outcomes of care. Major concerns expressed at the time included the definition and application of the term “unanticipated outcome,” what specifically should be disclosed, who should be involved in a disclosure discussion and what protections, if any, would there be for organizations or individuals who comply with the Standards.

Many organizations have developed written disclosure policies in an effort to comply with the Standards. Their policies often set the basis for disclosure at “when the patient is substantially harmed.” But what constitutes substantial harm? Some organizations define harm as “the need for additional treatment or hospitalization” whereas others define harm as the subjective perception by the patient or family that harm might have occurred. (*The second monograph in this series discusses ways to define “harm” in policies that address the need for clinician protection while allowing for specific patient needs.*)

Much debate about disclosure has focused on determining the conditions and severity of the unanticipated outcome that triggers the disclosure discussion.

Although organizations may accept “harm” as the *de facto* guideline for when disclosure “must” occur, it remains a reactive measure based upon compliance with external standards rather than a reflection of understanding of the spirit of open, honest communication. Harm may occur to patients in the absence of error. Pain (anticipated or not), reaction to medication or intervention and poor outcome can occur when all standards of care are met. Likewise, errors may not result in harm if they have insufficiently serious outcomes, or they may never reach the patient. Although judgment must be used about the extent to which patients and families should be advised of potential or clinically insignificant events, discussion about disclosure is incomplete at best – and misguided at worst – if the focus is only on when the patient must be told of an outcome in order to comply with standards. The more important question is: How do we build a system that supports honest communication between patients and practitioners such that discussion of error and harm are part of the process, and not separate concerns?

In an ideal collaborative relationship, healthcare providers would be expected to communicate with patients about near misses because patients could help block similar occurrences in the future. Errors that cause no harm to the patient as well as harm that might be caused by side effects or bad reactions to medications would be communicated, as well. In a culture of fear, these discussions are perceived as threatening – with the potential for punitive action prompting inaction and silence. In a

culture of averting harm and sharing responsibility, however, discussion of unanticipated events in well-intended and appropriate care is part of the ongoing dialogue. The public discussion of disclosure is moving toward that collaborative spirit.

Because the focus has been on compliance with the Standards, debate continues about whether it is essential that the attending physician or a physician from the team participate in the disclosure discussion. Is it better to call on a physician who is an unwilling or unskilled communicator, or should a hospital representative with stronger communication skills take responsibility for the disclosure? (In a compliance model, the presence of a “licensed independent practitioner” is required.) In fact, patients and families often feel the closest alliance with their physician. Furthermore, their physician is in the best position to advise the most appropriate next steps clinically. Other staff cannot handle this adequately. Furthermore, in most cases, the physician will feel tremendous responsibility, both personally and professionally, and may want to be involved. Experience is proving that the presence of an attending physician, whether or not that person is the one who leads the communication, is paramount to success of the encounter from the patient’s perspective.

Concerns over discoverability

The issue of discoverability and the validity of that issue have been hotly debated in many venues. Although there is growing agreement that the admission of an unanticipated outcome or even an error is simply a factual statement, insurers justifiably enjoin their insureds not to assume liability for the company, nor promise compensation on behalf of the company. The admission of liability comes at the point at which the insured makes statements about the acceptance of culpability or negligence and assumes financial responsibility. In a hard economic market where increasing numbers of organizations are self-insured, the use of disclosure and ultimate admission of error is being used to leverage early resolution of claims.

Healthcare organizations have questioned the value of sharing the findings of root cause analysis or process changes made subsequent to an error to a patient or family in a disclosure conversation. Although some individuals believe this information should be protected, others take the stand that process changes would be discovered during any litigation process and should be revealed. How these activities are conducted will depend on individual states’ protections for peer review as well as whether the root cause analysis process is considered a peer review activity. (For example, the state of New York requires that patients be told the results of investigations that often include root cause analysis.) Possible approaches include saying such things as: “In our investigation we learned we have an area in our pharmacy process that could be improved in order to prevent this type of error from happening again. We have instituted some of those changes already.” Where the root cause may identify an employee performance factor, an approach may include saying: “In our investigation, we learned that additional counseling/training would benefit our employees. We are taking steps to ensure that our employees are receiving the help they need.”

The disclosure of investigation outcomes should be factual and broad. Most patients do not need nor want details of the process improvement. As Vincent, et al found in 1994, patients stated that they desired to know that the healthcare organization responded to the event by making changes so that the same event would not happen again(1).

In June 2001, ASHRM held a national videoconference featuring a panel discussion about disclosure from the perspective of a risk manager, an insurer and a plaintiff’s attorney. Appraising the benefits of disclosure, the plaintiff’s attorney made a profound statement: Most often, patients find an attorney because they feel there is information that the hospital or clinician has denied them. The feeling of betrayal and distrust is exacerbated when a review of the record or deposition reveals that

information had not been disclosed. This sense of betrayal often contributes to the anger that fuels litigation and the desire for punitive action.

BARRIERS TO DISCLOSURE

Barriers to disclosure and open communication fall into two primary categories: psychological and legal. The combined psychological and legal aspects of the barriers are clearly demonstrated in the absence of a culture of safety in many organizations and through the absence of a patient-centered philosophy of care. In order for a true culture of safety to exist, patients, staff and physicians/clinicians must feel free to express concerns about potential harm and have no fear of discussing error. Similarly, patient-centered care requires that communication and attention be focused on the medical and psychological needs of the patients rather than the protection of the organization.

In moving the system away from blame and toward collaborative relationships, it's vital to understand that these changes are complex. The slow evolution starts within the organization and moves to the community through regular and ongoing reinforcement through action. Nonetheless, the psychological and legal barriers are real and must be addressed first.

Psychological barriers

Psychological barriers to disclosure are no different from barriers to any other difficult communication that involves bad news. While it is easy to agree that patients ought to be able to direct their care and make decisions about future care, it is fair to say that physicians and clinicians feel the weight of deciding when, if and how to tell patients about poor prognoses, unanticipated outcomes and medical error. Psychological barriers may include:

- **Fear of retribution from the recipient of the news.** “Will the recipient try to punish or harm me legally or physically?”
- **Fear of retribution from colleagues or peers.** “Will I be ostracized or otherwise criticized for my involvement in the unanticipated event, or for my action as part of the disclosure discussion?”
- **Fear of conducting the conversation poorly.** “What if I upset the patient or family if I don't convey the information effectively? Will the hospital be angry with me for communicating ineffectively?”
- **Fear of having to handle the recipient's as well as their own emotions.** “What if the patient or family member cries, becomes angry or threatens me?”
- **Belief that the disclosure is unnecessary.** “If we didn't tell the family, they would never know this had happened.”
- **Belief that disclosure is primarily a factual conversation and not a complex interpersonal conversation.** “If I just state the facts, haven't I disclosed adequately?”
- **Belief that the outcome is not related to action on the part of the discloser.** “If I were not directly involved in the event leading to the outcome, why should I be involved in disclosing the outcome?”
- **Belief that the outcome would potentially have occurred without the error or intervention.** “What difference would it make? The patient might have had the outcome anyway. He/She was very old and/or sick.”

Legal barriers

Legal barriers to disclosure are both real and perceived, entrenched in years of punitive attitudes and cultures of blame. These barriers may include beliefs that:

- **There is no legal protection for information provided during the disclosure of a medical error.**
- **There is no legal protection for information in the medical record.** Potential discovery can be mitigated by following procedures under state laws that permit limited protections for work related to peer review or quality improvement.(2)
- **There is no sharp line that determines when a disclosure is not necessary.** Is disclosure “necessary” for an error that does not reach the patient or for an error that results in no additional treatment?
- **There is no “benefit” for disclosure during the claims/litigation process, other than jury perception of an effort to be honest and forthcoming by the system.** (*This is discussed in greater detail in the second monograph in this series.*)

MODELS FOR MANAGING THE PROCESS

The movement toward a culture of safety and open partnership with patients is a process that every organization, practice group and community will assume at differing rates and with differing challenges and concerns.

For many organizations, compliance with the Joint Commission Patient Safety Standards is the beginning step. The challenge is to recognize that the process of developing open communication with patients is dynamic. Static policies, processes or approaches to communication with patients and families reflect a culture that is failing to mature in its approach toward partnering with patients. Consequently, the expectation is that ongoing improvement of communication skills among practitioners and staff is a part of the goal of every approach to management of the disclosure process. Furthermore, as the culture of patient safety grows within an organization, the policies and procedures should begin to reflect a broader approach to “open communication” with patients, and the models for supporting open communication with patients might evolve and change.

Nonetheless, healthcare organizations recognize that the management of the disclosure process is essential for physicians/clinicians and staff to feel supported by the organization and for disclosure discussions to have the best opportunity for effective handling. Coaching, emotional support and guidance will always be essential components of a system that values effective communication with patients and families.

Given the needs of organizations based upon their size, their current place on the continuum toward a culture of safety and the needs of the medical staff, organizations have found different models for supporting the activity. Four effective models for disclosure responsibility have emerged:

One-Person Model

- **Description:** The organization designates one person, frequently the risk manager, as the anchor for all disclosure communication. This model places tremendous accountability for coaching clinicians and others for disclosure discussions, or participating in disclosure discussions on one person.

MONOGRAPH

- **Benefit:** The organization can assure itself that the designated person can be trained to have the communication skills for effective disclosure.
- **Drawback:** There is no room for shared responsibility nor imbuing the entire organization with the disclosure philosophy and skills so that honest communication becomes part of the fabric of daily interaction with patients.
- **Best organization fit:** In a small organization, the single point person method might be the most efficient way to ensure consistency and quality of communication.

Team Model

- **Description:** This approach requires intense training of a select group of individuals in the effective disclosure skills and the communication policies of the organization. Usually team members are chosen from among the organization's identified effective communicators. They are likely to be from a variety of services and known for their interpersonal skills. Subsequent to training, team members are assigned to coach physicians/clinicians or staff and accompany them in disclosure discussions.
- **Benefits:** The organization can be assured that effective communicators are involved in every disclosure discussion. In addition, the clinician is coached and accompanied by a colleague with identified skills in effective communication. Finally, the team shares responsibility for participation and coaching of disclosure communication so the best "fit" for any situation can be selected to participate in that discussion.
- **Drawback:** Healthcare staff may be diverted from daily responsibilities to participate in a disclosure discussion. Depending upon the nature and volume of the work, that diversion could be a burden.
- **Best organization fit:** In a small- to medium-sized organization, this model could easily be an effective way to teach honest communication through role model behavior.

Train the Trainer Model

- **Description:** The organization invests in the comprehensive training of a large group of physicians and other staff. The trained individuals train, and are rewarded for training, a certain number of people in the organization each year. The philosophy is that these trainers are doubly valuable to the organization. First, they are selected for their amenability to interpersonal skills training and they become highly trained. Next, those individuals provide a service to the organization by training other staff. As they train, they become more comfortable in the concepts of disclosure. In addition, they become mentors and role models.
- **Benefits:** This model uses individuals throughout the organization, including physicians and clinicians, to spread the skills and the philosophy of honest communication through the organization. In addition, it provides an economical way to ensure that all staff and employees are introduced to the concepts of honest communication with patients.
- **Drawbacks:** Quality control and distribution of responsibility are the main drawbacks. This model must include a single individual who is ultimately responsible to ensure that the trainers are training at the level expected and that training opportunities are scheduled throughout the organization. Nonetheless, this model offers an opportunity to effect pervasive cultural change.

- **Best organization fit:** Large- to medium-sized organizations with several campuses might find this method the most efficient and effective for providing consistent education. In addition, this method could be effective to generate physician/clinician buy-in if respected members of the medical staff are trainers.

Just-in-Time Coaching Model

- **Description:** In this model, the individual practitioner at the site of the event discloses what is known at the time. The discloser may be a nurse, attending physician or other practitioner with whom the patient has a relationship depending upon the significance of the event and seriousness of the outcome. There generally is an in-house coach, frequently the risk manager, with whom practitioners can discuss the disclosure prior to the discussion.
- **Benefits:** This model is direct and easy. It places the responsibility for effective communication skills at the point of care. It is the ultimate in mature patient/family partnering.
- **Drawbacks:** This model is dependent upon the skill of the individuals at the point of care. Where communication skills are effective, this is an ideal model. Where there is the potential to lay blame or fail to support the organization's improvement efforts, or where communication skills are insufficiently empathetic, this model can result in less effective patient/family partnering.
- **Best organization fit:** Any organization that is mature in its patient safety culture could use this approach. By the time the organization has passed through the various stages of cultural maturation, the staff and physicians/clinicians will be knowledgeable of their own strengths and shortcomings and will know when and how to seek coaching.

EXPERIENCES WITH DISCLOSURE

After the initial two years of disclosure of unanticipated outcomes since release of the Standards, many stories have emerged that tell of successful communication and satisfactory results for organizations. Other experiences are felt to be less successful for organizations.

The Standards do not define "success." Nonetheless, they set an expectation for communication by requiring organizations to ensure that patients and families are informed about the outcomes of care. By doing this, they are, in essence, supporting the rights of patients to be involved in all aspects of their care. Healthcare providers, however, have created internal standards for "successful" disclosure that are not based upon the intent of the Joint Commission Standards, but upon their own hopes and desires. Many organizations have linked lack of seeking compensation or retribution as "success" while the pursuit of litigation or compensation is seen by many as lack of success. Definitions of a successful disclosure conversation vary and may include:

- The patient and family do not sue
- The patient and family understand that mistakes happen and do not get angry
- The patient and family don't go to the press
- The press praises the caregivers' action and honesty.

This measurement for success is based upon self-serving outcomes. It fails to recognize the true purpose of disclosure: the open communication about all aspects of care with patients and families. A successful disclosure process could best be described as one that enables the patient and family to

understand what happened and the ramifications of the event as well as have sufficient information to make future decisions. Future actions might include seeking compensation. When caregivers humanize the situation, there is a greater likelihood that the demand for compensation is to cover financial damages rather than to be punitive. Indeed, there is no guaranteed reaction. Given that, the true success of disclosure can only be measured in the efficacy of communicating facts and sharing regret for the patient's/family's trauma.

In the spirit of improving patient safety and creating a "learning organization," it would help to think of all disclosure communications as opportunities for improving communication with patients at all points of the healthcare continuum. If healthcare providers can get to the place where they begin their relationships with patients talking about the potential for error and the need for interactive communication and partnership, the stage can be set for more effective interaction should the need for the disclosure of an unanticipated event arise.

Examples of communicating disclosure

Analyses of disclosures that have not worked as well as anticipated often show that less effective communication choices were made by the discloser which resulted in defensiveness on the part of the patient or family.

- **The ophthalmologist.** The ophthalmologist at a large facility performed laser surgery on a 65-year-old woman. The consent process included the possibility of error, which ultimately occurred. The patient's vision did not improve as predicted. The physician disclosed the error to the patient and was surprised to learn later that she was angry and considering pursuing a claim. He called her to discuss what happened. She felt that during the disclosure conversation the ophthalmologist seemed more interested in impressing upon her that it had never happened to him before – he seemed more concerned about himself than about her. Fortunately, this physician followed up with her and was able to apologize and remediate the situation.
- **The baby.** A medication error resulted in the death of a 5-week-old premature infant in the NICU. The physician was coached by the risk manager and seemed to know how to approach the situation. In the family meeting the physician felt cornered and threatened by an angry father. In his discomfort, he admitted liability. The organization was upset with him for handling the disclosure badly.
- **The understanding parent.** A baby in the NICU was the recipient of two medication errors in a 12-hour period. One healthcare clinician's opinion was that error was simply part of what happens in hospitals and should be handled matter-of-factly. A colleague, on the other hand, believed the parents would understand if the matter were approached more sensitively and accompanied by an apology. The risk manager suggested that both physicians participate in the disclosure, with the second physician leading the conversation. The discussion resulted in tears. The mother of the baby realized that the infant was very ill and that the hospital had allowed her to have more time with the child than she might have otherwise. She did not pursue litigation.

CONCLUSION

The passage into a culture where open communication with patients is the norm is still in the early, learning stages. This monograph focused on where healthcare providers are in their current development, the disclosure of actual unanticipated outcome. As healthcare providers move forward to an era where “disclosure” is not an issue on its own, but simply one aspect of the communication process with patients, they will move into a time where appropriate, uniquely collaborative relationships with patients will involve the spectrum of communication – from involvement in selection of outpatient alternatives to traditional treatment, through facilitated education prior to consent for treatment, and full involvement in the complex process of inpatient care. Healthcare cannot get there in one step. Nevertheless, it is an evolution that must be undertaken.

DISCLOSURE OF UNANTICIPATED EVENTS: HISTORICAL PERSPECTIVE

The issue of disclosure was rarely discussed before 2001, when the Joint Commission ventured to make requiring the disclosure of unanticipated medical outcomes an industry standard.

Historically, the research on how much information to provide to patients was done in the area of oncology. The prevailing belief system was that patients and families might be inclined to lose hope if they believed that the potential outcome would not be perfect. Other rationale for not disclosing included the potential for the patient to lose trust and confidence in the physician or clinician(3). Confounding this belief system was the prevailing form of medical education at the time that supported a distancing of physicians/clinicians emotionally from patients and their care. The medical education philosophy stated that any type of consideration of patients or their feelings would detract from the healthcare provider’s ability to make rational, detached decisions about care(4).

What healthcare providers have learned

Patients and their families have interpreted much of this distancing as an attempt by healthcare providers to protect themselves from patients. Research has found that:

- 98 percent of patients desire to be informed of even a minor error; the greater the severity of the outcome, the more patients and families want information(5)
- While 92 percent of patients believed they should always be told about complications, only 60 percent of the physicians believed that patients should always be told(3)
- Furthermore, 81 percent of the patients believed they should be advised of the possible future adverse outcomes of the complications, while only 33 percent of the physicians believed that patients should be told about possible future adverse outcomes(3).

Healthcare providers’ lack of engagement is seen as disparaging of a patient’s perspective and not recognizing the extent of the patient’s or family’s trauma in the face of medical error or unanticipated outcome. Studies conducted in the 1990s show that patients want to know the truth, want the healthcare organization to take responsibility for its actions, and want an apology in recognition of both their trauma and healthcare practitioners’ participation in the experience. The desire for human interaction precedes the need for monetary compensation(1).

The literature continues to support the desire for improved communication. Patients continue to feel that the greatest problem in healthcare is lack of communication among the healthcare team, and insufficient time to communicate with their physician(6). Furthermore, complaints and allegations of malpractice continue to be linked with lack of communication as well as poor communication skills(7-8). Yet despite the ongoing research supporting the need for communication between practitioners and patients, we continue to struggle with how much, what, and when to talk with patients about outcomes and errors. A key to this may also be in the literature. Research shows that when there is an error or unexpected outcome, both patients and clinicians have needs for support and guidance that are yet unmet(9).

Moving from 'disclosure' to 'communication'

Not only is there movement from a historical period where it was both the prerogative and the duty of the physician or clinician to decide for patients what was in their best interest, interpersonal communication skills are now becoming essential for partnering in a new way with patients.

Old forms of communication in healthcare focused on a hierarchical relationship with the physician at the top of the pyramid and the patient at the bottom (receiving end) of care. Communication did not involve the patient and often did not involve many of other members of the healthcare team.

In the culture of safety promoted by the Institute of Medicine Reports – where learning from mistakes, working together to create safe processes and involving the patient in all aspects of care is expected – a different approach to communication must be integrated into the system. Part of that new approach includes disclosure.

The next wave of activity around disclosure will involve determining how to integrate the concept of open communication into all aspects of the healthcare environment. This will include moving from “disclosure policies” to “communication policies”; from concern about discoverability and liability to concern about accountability and fair compensation before the start of litigation; and from concern about whether to disclose to concern about what patients need to know in order to best partner in directing their care.

REFERENCES

1. Vincent, C., Young, M., Phillips, A. Why do people sue doctors? A study of patients and relatives taking legal action. *Lancet*, 1994; 343 (1): 609-13.
2. ASHRM. Strategies and Tips for Maximizing Failure Mode Effect Analysis in Your Organization. Whitepaper/monograph, www.ashrm.org, July 2002.
3. Hingorani, M., Wong, T., and Vafidis, G. Patients' and doctors' attitudes to amount of information given after unintended injury during treatment: cross sectional, questionnaire survey. *BMJ*, 1999; 318:640-641.
4. Halpern, J. From Detached Concern to Empathy: Humanizing Medical Practice. New York: Oxford Press, 2001. pp 22-23.
5. Witman, A.B., Park, D.M., Hardin, S.B. How do patients want physicians to handle mistakes? A survey of internal medicine patients in an academic setting. *Archives of Internal Medicine*, 1996; 156 (22): 2565-9.
6. Blendon, R.J. et al. Views of practicing physicians and the public on medical errors. *NEJM* 2002; 347 (24): 1933-40.

MONOGRAPH

7. Taylor, D.M., Wolfe, R., Cameron, P.A. Complaints from emergency department patients largely result from treatment and communication problems. *Emergency Medicine*, 2002; 14(1): 9-11.
8. Ambady, et al. Surgeons' tone of voice: a clue to malpractice history. *Surgery*. 2002; 132 (1): 5-9.
9. Gallagher, T.H. et al. Patients' and physicians' attitudes regarding the disclosure of medical errors. *JAMA*, 2003; 289(8): 1001-1007.

ADDITIONAL RESOURCES

The Risk Management Handbook for Healthcare Organizations. San Francisco: Jossey-Bass.
www.ashrm.org/store or call (800) AHA-2626.

Risk Management Pearls on Disclosure of Adverse Events. Chicago: ASHRM.
www.ashrm.org/store or call (800) AHA-2626.

ACKNOWLEDGMENTS

Geri Amori, Ph.D, ARM, FASHRM, CPHRM
Monica Berry, BSN, JD, LLM, DFASHRM, CPHRM
Jeffrey Driver, JD, MBA, DFASHRM, CPHRM
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For details on the Team Model for disclosure responsibility, contact Roben Nutter, East Alabama Medical Center, 2000 Pepperell Pkwy., Opelika, AL 36801; (334) 705-1815.

For details on the Train the Trainer Model for disclosure responsibility, contact Peter K. Wong, Ph.D., Sisters of Charity of Leavenworth Health System, 9801 Renner Blvd., Suite 100, Lenexa, KS 66219; (913) 895-2800.

NEXT IN THE SERIES

- **“Disclosure Policies: An analysis of the influence of disclosure on litigation.”** This part will cover disclosure policies. It will provide models, discussions of strengths, and suggestions for building an effective policy. It also will present the findings on the effect of disclosure on litigation and claims activity. Finally, it will discuss the implications of disclosure in different settings: acute care, long-term care and pediatric care.
- **“Effective Disclosure: What works now, what can work better.”** The focus will be on techniques that improve effective disclosure and how they can be applied. In addition, this monograph will analyze different disclosure situations, providing discussion on the issues to consider and the techniques that will enhance the potential for effective communication with patients and families.

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Monograph

Disclosure

of unanticipated events:

Creating an effective patient
communication policy

second of three parts

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FOREWORD

In this three-part series on disclosure, Part 1 – “The Next Step in Better Communication with Patients” – described the initial impact of the 2001 National Patient Safety Standards established by the Joint Commission on Accreditation of Health Care Organizations; the psychological and legal barriers of open communication; models used by organizations to support and influence communication; and an analysis of some disclosure experiences.

With this broad overview of the philosophy of disclosure, the challenges to nurturing a culture of open communication and the approaches some organizations have taken to work the practice of disclosure into the operation, the stage is set for analyzing the value, structure and challenges inherent in developing a disclosure policy for the organization.

This paper, Part 2 in the series, addresses:

- Considerations for developing policies and procedures regarding disclosure.
- Suggestions for building an effective policy.
- Special considerations for developing policies in specific settings such as acute care, long-term care and pediatric care.
- The effect of disclosure policies on litigation, including ways to define harm for the purpose of policy development.
- Ideas for staff and provider training and policy considerations in specific patient settings.

The third paper, titled “Effective Disclosure: What works now and what can work even better,” focuses on techniques to improve effective disclosure and how they can be applied.

In addition, the third monograph analyzes different disclosure situations, providing discussion on the issues to consider and the techniques to enhance the potential for effective communication with patients and families (however patients define them). It further discusses the ramifications of disclosure on litigation and in acute, long-term care and pediatric care settings.

INTRODUCTION

Historically, organizations developed policies and procedures for regulatory and accreditation compliance purposes. From a risk management standpoint, a fear was that lack of effective implementation/enforcement of the policies and procedures could create liability exposures for the organization.

For example, if a policy required that a patient be checked every 15 minutes while under observation and, due to staffing shortages, staff members could only check the patient every 30 minutes, they are held to be in violation of their own policy by plaintiff's attorneys and juries. The reasoning: If the organization established the policy, it should be followed at all times. This was deemed true even if there was a logical reason in a particular situation for non-compliance.

The development of policies and procedures in healthcare has sometimes substituted for the arduous task of identifying and addressing latent failures in a process.

For example, when an unanticipated event occurs, it's not unusual to see the creation of a new policy or procedure to address the very specific situation that resulted in that one event. The reactionary development of policies and procedures often results in extremely detailed and proscriptive procedures that do, in fact, create a narrow window of appropriate behavior in a given circumstance. Due to the inherent variability of factors in any given situation, there is likelihood of compliance failure and thereby increased liability exposure. The more specific the policy to a situation, the less likely it is the policy will have general applicability and be followed on regular basis.

Instead, policies and procedures should reflect the values and principles of the organization, including its care philosophy. Accompanying procedures should provide guidance about implementation of the policy, and those procedures should not be so restrictive as to be prohibitive in actual practice.

BUILDING AN EFFECTIVE POLICY

Semantics: Mistake management, informing patients, disclosure and communication

When drafting a policy, it is important to determine the language that will be used and the effect of that language.

Using the word "disclosure" can often give the impression that the consequences of not having such a policy would indicate "non-disclosure." Instead, using proactive terms such as "communication" may avoid this impression and convey a positive cultural statement.

Note, for instance, how a patient disclosure/communication policy statement that reads *"It is XY Hospital's goal to always have open, honest and constant communication with our patients"* is much more positive than one that says *"It is the policy of XY Hospital to disclose any unanticipated outcomes."*

While this may seem too basic, the policy may be produced in a lawsuit in the future and a jury may try to interpret its meaning and application. The focal point becomes the interests of the patient versus protection of the organization from litigation. The policy should be stated in positive and proactive terms.

Example:

Hospital XXX	Policy & Procedure Manual
Policy for Effective Patient Communication	
<p><u>Purpose:</u> It is the goal of Hospital XXX that all patients feel involved in their care and treatment through frequent and effective communication. This communication may take the form of informed consent, communication of an unanticipated event, and the daily talks with physicians and staff on how their treatment plan is progressing.</p>	

In addition, the language used in the policy needs to be the same as language employed throughout the organization to help ensure consistency of the message. Using language that is not consistent with the safety philosophy will create confusion. Language communicates not only the content message, it conveys and reinforces the culture, too.

Consistent communication, informed consent through disclosure

Effective disclosure/communication begins with informed consent, which is basically a proactive form of disclosure of an unanticipated or undesired outcome.

The disclosure should be considered part of the informed consent process between the patient and practitioner. This process includes much more than just the informed consent for a single procedure. It includes involving the patient in daily decisions that affect the overall treatment plan, obtaining his or her cooperation in their own well-being and facilitating an open forum for patient or family questions or concerns.

Moreover, risk management professionals can use documentation of the informed consent to guide practitioners during the disclosure of an unanticipated or undesired outcome, so that the message to the patient remains consistent.

Ultimately, the communication or disclosure policy should be drafted to be consistent with the organization's informed consent policy, but also with the goal of instilling a culture of constant communication between hospital staff and patients and their spouses, partners, children or any others they consider "family."

Medical staff approval

Obtaining approval for the policy from the medical staff may require some education before support will be given. Actually, the physician leadership should be engaged in establishment of the policy. For example, they might be involved in identifying the expected role of the physician membership in disclosure conversations.

To be consistent with the spirit of a safety culture, discussion should focus on the issue of the organization's care philosophy and how physicians can support that philosophy. If the policy has been worded with that philosophy in mind, the "sell" to the medical staff will be facilitated and the willingness to support the policy will likely be increased.

Very often, physicians are concerned that they will be the targets of blame in disclosure situations. They need to be assured of support in their efforts – before, during and after the conversation itself and in the followup investigations or reporting that may be necessary as a consequence of the event.

Furthermore, physicians must be assured that although they, as attending, may take the lead in the discussion, the organization sees any occasion on which news of harm is delivered as a team occurrence for any staff that may have been involved in the event.

Therefore, a condensed training session should take place with the key medical executives in order to give them information not only about the basis and need of the policy, but also to allow them to understand (and thus communicate) the roles that they and other providers will fill.

At this time, the philosophy of patient communication is more than informed consent for a procedure or the disclosure of an unanticipated outcome. The involvement of the patient in daily decisions that affect the overall treatment plan builds a framework in which discussions about bad news (poor prognosis, complications of treatment, medication reactions, medication errors, less than optimal outcome of treatment, treatment error, etc.) are as natural as discussions about good outcomes and routine care.

Policy contents

A complete policy should include the following:

- **Policy statement/objectives.** This should be a brief statement that describes what the policy is, when it applies and what it is intended to do. Policy statements are most effective when they are limited to a single sentence. The policy statement is the quick guide to staff and employees that indicates the relevance of the policy to the situation about which they are concerned.

Example:

Hospital XXX	Policy & Procedure Manual
Policy for Effective Patient Communication	
<u>Objective:</u> "Hospital XX believes that patients are entitled to information about the outcomes of diagnostic tests, medical treatment, and surgical intervention. Hospital XX and its providers recognize the importance of maintaining good communication with patients and when appropriate their family by providing information that fosters informed decision-making."(1)	

Note that the language of the policy ideally is stated in the affirmative, rather than the negative. For example: *"Only factual medical information about the patient's direct care and status should be documented in the chart"* is a better way to state that information about discussions with risk management should be eliminated from the documentation. If the policy were to state *"Do not document that risk management was notified,"* a plaintiff's

attorney or jury is likely to interpret the message as one of the organization discouraging communication and possibly trying to cover up information.

- **Definitions.** The policy should give definitions for any terms used within the policy and procedure that may be unclear. Although many organizations use definitions that come from Joint Commission standards or the literature, other organizations create definitions that address the specific structure of their organizations.

Terms listed below generally are defined in a comprehensive disclosure/communication policy. Not all need to be included if they are not terms used at a specific facility (and some may be duplicative), but all are listed here for suggestion of inclusion:

Adverse Event or Error or Unanticipated Event
Near Miss
Sentinel Event
Significant Adverse Event
Disclosure
Patient Safety Committee or Officer
Informed Consent
Primary Caregiver
Outcome
Patient Care or Treatment Plan

Furthermore, if the organization uses terms that differ from those used by other organizations or reflect the unique culture of the organization, then those terms should be defined in the body of the policy.

- **Criteria of an event warranting “disclosure.”** This statement should also be brief, and should include language general enough to allow for the inclusion of multiple situations. An example statement may be: *“Discussions with the patient or family may be warranted if there is a change in the treatment plan or unanticipated event or outcome of which the patient may not otherwise be aware.”*

Some organizations are choosing to move to statements of disclosure/communication when “harm,” however it is defined, has occurred to the patient. Many organizations are indicating the need for “disclosure” with a stepped analysis of harm moving from errors that never reached the patient (no obligation to discuss) to outcomes such as natural sub-optimal results to treatment or from medical error (must be discussed).

- **Process steps for disclosure conversations.** The policy should then give guidance on steps to be followed to allow for the disclosure conversation to be effective and consistent.

Here, the policy may need to identify:

1. **Designated personnel roles.** Who should be part of the conversation? An example might state: *“It is preferred that the attending physician responsible for a patient’s care will fully and honestly explain the outcome of any treatments or procedures to the patient, and when appropriate, to the designated decision-maker. In most circumstances, the primary attending physician will lead this explanation. Another member of the hospital staff or medical staff (such as a nurse, consulting physician or*

physician performing a specific procedure) may explain the outcome if deemed more appropriate by the primary attending physician.”(2)

2. **Conversation outlines.** Key areas to cover, but with the opening statement examples left to specific provider training sessions. An outline might include:
 - a. Statement of what happened (objective statement of the event/outcome).
 - b. Clear conveyance of regret.
 - c. Identification of steps already taken to prevent reoccurrence.
 - d. Discussion of any change in the patient’s care plan and addressing of any areas of particular concern to the patient.
 - e. Identification of whom the patient or family will hear from next in the organization and what (if any) steps they will need to take.
 - f. An offer of support services to the patient and applicable family members. The book *What Do I Say? Communicating Intended or Unanticipated Outcomes in Obstetrics* suggests the acronym **FEARED** to remind providers of the steps involved in disclosure conversations. These steps include:

Get all of the **F**acts.

Express **E**mpathy and **E**ducate.

Search for sources of **A**nger.

Have patients **R**elate back their understanding of the explanation.

Evaluate the **E**xtended family response.

Document the conversation.(3)

3. **Accommodations for special communication needs.** Advice on dealing with special situations where language barriers, disabilities or other communication challenges may be encountered, including the identification of accommodation resources such as interpreters.
 4. **Support services available to the patient.** A list of resources that could be given to the patient or family for pastoral care, social services or other support services available in the community.
 5. **Steps for followup conversations.** Advice on how to leave the door open for future conversations with the patient or family on the issues being addressed, including contact information for the patient or family plus contact information for future provider support or questions.
 6. **Documentation of the conversation.** Appropriate location, timing and technique to ascertain that the documentation reflects the content of the conversation, any treatment plans discussed, the participants, the level of understanding exhibited by the patient and the next steps to be taken by the patient and any providers or the facility staff.(4)
- **Conflict resolution steps.** Periodically, a disclosure conversation will result in the need for diffusing conflict or even the need to involve pastoral care or security (depending on the degree of conflict present). It is important for the policy to indicate that appropriate steps will be taken to resolve any conflict, including when to involve staff beyond the involved providers.
 - **Dates of review and implementation.** The policy needs to reflect dates when the policy was implemented, when it has been reviewed (as specified in an organizational structure) and

when it will be reviewed again. This policy should be reviewed at least twice the first year to be sure that the wording in the policy truly reflects the actions being taken.

- **Circumstances where disclosure may not be appropriate.** The policy may state circumstances where the harm of the disclosure outweighs the benefits, and how to handle the making and documentation of this decision. An example might include: *“In extremely rare situations where a physician can clearly demonstrate that the interests of the patient or, when appropriate, the family, are harmed by disclosure, this discussion may be withheld until the benefits of disclosure are greater than the harm. Any exceptions to the presumption of disclosure must be specifically justified and documented and reported to the hospital’s peer review committee.”*⁽⁵⁾

Staff and provider training

Any policy of disclosure/communication requires education at all levels of the organization. Implementing the policy means much more than simply drafting the language. It means communicating the goals and the steps to the involved personnel. It also means making sure that levels of management understand not only the reasons for the policy but the potential implications – including what resources are needed to effectively implement the policy – too.

Training goals should include identification of disclosure situations, staff understanding of how to implement the appropriate strategy or communication technique, and staff acceptance of their role (involved or not) in disclosure conversations. Additionally, the goals must illustrate a measurable behavior change in communication techniques and give a forum to discuss remaining barriers to change in a debrief meeting with key clinicians or administrative personnel.

Audiences and applicable topics may include:

1. **Board leadership.** Covers the financial exposures of litigation and the role of the crisis team. Identifies the board’s role, exposures and the care philosophy that supports the need for patient-centered communication.
2. **Organization leadership.** Covers the financial exposures of litigation, the role of the crisis team and identification of the crisis team members. Encourages a culture of disclosure/communication by emphasizing the organization’s care philosophy and mitigating litigation exposure. May include administrative team, medical staff leadership and employed providers.
3. **Physician/medical staff.** Covers the physician’s role in actual disclosure, fostering increased patient involvement and mitigating liability exposures.
4. **Hands on caregivers.** Covers the hospital staff practitioner’s role in actual disclosure, emphasizing the balance of finding the “appropriate time and appropriate message in the appropriate way.”

The training should be centered on the policy language, both on learning the policy and understanding the cultural environment that needs to be in place in order to affect the policy. For an organization that is not yet there culturally, the training should emphasize adoption of the policy by the medical staff and board. When they adopt the policy, they make a statement that they support a patient-centered philosophy. The implementation of the policy will reinforce the culture. Training should be adapted to the audience and should include easily remembered themes and role-playing so all participants can become familiar with their roles and the intent of the policy.

POLICY CONSIDERATIONS FOR SPECIFIC POPULATIONS AND SETTINGS

When developing disclosure/communications policies for specific populations and settings, the organization should consider the unique aspects of care, types of potential unanticipated events, and unique psychologies of patients and their self-defined families.

Pediatric settings

Special attention should be paid to establishing when children should be involved in provider-family communications and when this is not appropriate. A decision tree may be referenced, outlining criteria such as the child's age, mental status, knowledge and involvement in their condition and treatment plan.

In addition, custodial issues need to be addressed, including when conversations can take place without the custodial parent present (if at all), etc.

Long-term care settings

A key issue may be the capacity of the patient to understand discussions about events in care. Policies need to state clearly how the organization determines the appropriate persons to participate in the disclosure discussions. Again, a decision tree may be referenced, outlining the patient's mental status, involvement in his or her condition and treatment plan, family requests for involvement, patient confidentiality, etc.

Special attention needs to be paid to telephone notification about the need for a discussion. In some instances, the appropriate parties to participate will be unable to come to the facility for a face-to-face discussion. How those situations are to be handled must be addressed in such a way that the communication plan does not create undue hardship on the family.

Psychiatric settings

Much as in long-term care settings, the psychiatric setting policy should address when the patient is involved in the discussion and include a decision tree for patients without current or permanent capacity. The notification of family or custodians may bring confidentiality issues if communication channels are not identified early in the patient's care.

Finally, the policy needs to address to whom disclosure should be made if the patient has no family or next of kin.

SPECIAL CONSIDERATIONS FOR THE RISK MANAGER

Policies and litigation

It is not unusual early in a malpractice case to receive a request for policies and procedures that may have relevance to the event being litigated. Before simply turning over the entire policy manual, it is best to think about just which policies may apply to the event in question.

There may be policies that actually help the defense of the case, and those should be provided. An effective policy may be one that is produced in any situation that has an unexpected outcome or

disclosure conversation. This can help ensure that the jury hears that the organization does believe in open and constant communication.

At the same time, it should be realized that a feeling of frustration with either the care rendered or the lack of information surrounding an event or outcome is the reason most cases result in litigation. Therefore, when producing the disclosure/communication policy in a pending malpractice case, be sure you have identified who may have been involved in communications with the patient on the issue at question and how those conversations went toward involving the patient in care and treatment as well as communicating any difficulty or unanticipated event. It would also be beneficial to show documentation of all communication in the patient's chart.

Reconcile how the situation was handled with the policy/procedure to prepare the defense, and examine documentation of reasons that could explain why the policy may not have been specifically followed.

Always consult with defense counsel on just what policies to produce in response to a Request for Production. Talk about the policies, their applicability to the case at hand and how they can assist in the defense of the case.

The effect of disclosure discussions (as distinct from policies) on litigation and claims is discussed in more detail in Part 3 of this ASHRM monograph series, where it can be analyzed in light of the skills for effective disclosure.

Support services for involved staff members

The occurrence of an unanticipated event can have significant emotional and psychological impact on the involved providers and staff caring for the patient. Any providers or staff who need support services should be given those through the facility.

Required reporting or necessary investigations

Depending on the situation, state or federal reporting may be necessary.

Training for staff

Training in communication skills should be provided for staff on an ongoing basis to be sure that any and all communication with patients and families is as efficient as possible (and therefore complies with the overall organization goals and vision). Specific training in disclosure may be provided. However, training should also be provided for improving the consent process across the spectrum of care (not just for invasive procedures), methods for engaging patients and their families as collaborative partners in the care process, and dealing with patients who may present challenges to us because of their communication style, demeanor, or other attributes.

Communication skills that are needed in the healthcare organization are varied and complex. Training should be provided for any hospital staff that works with patients and families.

SUMMARY AND CONCLUSION

A well thought-out disclosure/communication policy will provide the healthcare facility with a means to prove the organization's values about communication with patients and their self-defined families.

A good policy also will provide a guideline to ensure that the rights and needs of patients are met during that encounter.

Policies should be simply stated expressions of organizational values. A helpful procedure is short and easy to understand. It addresses the key question in the mind of the practitioner who is managing the difficult situation and is broad enough to allow room for applying situationally based judgment.

All staff should be trained on the existence and purpose of the policy. All staff and employees – from the attending physician to the hands-on caregivers – must be aware that open and honest communication is not an option, but rather is integral to the value system and culture that the organization is striving to maintain. Training on the techniques of disclosing unanticipated events should be provided regularly to staff members who may need to be involved in such communication.

Policies created for special population group settings should address potential difficulties in creating an atmosphere of open communication. Common issues concern patient participation in the discussion, the appropriate parties to be part of the discussion, the ethnicity of the predominant patient group/self-defined family, and the lack of availability of family in proximity to the facility. Each organization should look at the unique characteristics of its facility's setting to determine what potential situations are likely to occur.

While policies will not protect against liability, a well-designed policy can be an ally in a court of law. A policy that addresses key issues and is followed is better evidence of good faith than a highly detailed policy that is ignored. On balance, a short policy that everyone knows about and strives to adhere to is better than an either overly comprehensive policy or none at all.

Effective patient communication is a process. It begins with the initial meeting and ends only when the therapeutic relationship is over. Policies supporting disclosure are only the first step. The ultimate result of an organization's embrace of honest communication is patient/customer satisfaction and well-being – as ASHRM's vision statement puts it: "Safe and trusted healthcare."

REFERENCES

1. HealthEast Policy and Procedure, Disclosure of Outcomes to Patients.
2. HealthEst.
3. Woods Jr., James R. and Rozovsky, Fay A. What Do I Say? Communicating Intended or Unanticipated Outcomes in Obstetrics. San Francisco: Jossey-Bass, 2003; p 45.
4. Perspective on Disclosure of Unanticipated Outcome Information, ASHRM whitepaper/monograph, www.ashrm.org, April 2001
5. HealthEast.

ADDITIONAL RESOURCES

The Risk Management Handbook for Healthcare Organizations. San Francisco: Jossey-Bass. www.ashrm.org/store or call (800) AHA-2626.

Risk Management Pearls on Disclosure of Adverse Events. Chicago: ASHRM. www.ashrm.org/store or call (800) AHA-2626.

ACKNOWLEDGMENTS

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Monograph

Disclosure:

What works now

&

What can work

even better

third of three parts

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FOREWORD

This paper is the third and final installment in a monograph series on the topic of disclosure. All are available as PDF documents on the Web site of the American Society for Healthcare Risk Management (www.ashrm.org).

The series reflects ASHRM's commitment to leading the quest toward safe and trusted healthcare.

Part 1 – “The next step in better communication with patients” – provides an overview of the evolution of disclosure since 2001. It covers the initial impact of the Joint Commission's Patient Safety Standards inaugurated in 2001, the psychological and legal barriers to open communication and models used by different organizations to address the issue of disclosure as part of the communication process.

Part 2 – “Creating an effective patient communication policy” – presents the core elements of a policy and key considerations for writing and implementing an effective policy in a variety of settings. In addition, the monograph addresses legal considerations regarding the development and use of a policy.

Part 3 – “What works now and what can work even better” – is provided here as a communications guide for those who may be involved in the disclosure process. It looks at components of effective communication of an unanticipated outcome, considerations for each of those components and the unique perspectives to be taken in various clinical settings. It is intended as a basic review of the skills required to communicate effectively with patients and families after an unexpected result.

Although these monographs focus on communication about unanticipated outcomes, they can provide guidance for development of policies, infrastructure and training programs for all communication with patients and their families.

Furthermore, when clear communication is a natural extension of the organization's philosophy of care, it will be reinforced and more effectively assimilated throughout the organization.

INTRODUCTION

Why are patient communication skills worth caring about? Historically, communication with patients has been taken for granted, the assumption being that healthcare providers would decide what was appropriate for patients and families to know. Only those related biologically were considered family. Furthermore, it was assumed that anyone trained in medical care would have the adequate skills to deliver required messages. “Good bedside manner” and “kindly behavior” was often seen to be a wonderful addition to care, not a prerequisite.

Times have changed. Increased technology and the advancement of medical sophistication have created artificial barriers between the patient and the caregiver.

This environment is changing in part due to the Institute of Medicine (IOM) 2001 report titled “Crossing the Quality Chasm: A New Health System for the 21st Century,” which identifies six aims to improve patient safety in healthcare: safety, patient-centeredness, timeliness, equity, efficiency and effectiveness.(1)

Additionally, the incorporation of disclosure of unanticipated outcomes in the Joint Commission on Accreditation of Healthcare Organizations Patient Safety Standards (2001) has forced the healthcare community to re-evaluate its attitudes about what is appropriate to share with patients:

- Where caregivers once assumed the right to decide what might be good for the patient, both in terms of action (which treatment to accept) and in terms of the effect of information (what information to withhold), the patient is now recognized as the arbiter of how information that pertains to them should be conveyed and used.
- Where caregivers once believed their relationship with the patient/family was secondary to their relationship with the payer (insurer), they now recognize that their primary customer is the patient. Caregivers and the patient/family together decide how to approach care that the payer may or may not support.
- Where caregivers once believed families were only those closely related biologically, they now must think of families as those that the patient considers related biologically, emotionally and/or legally (as defined by the Institute for Family-Centered Care).
- Finally, caregivers are learning that a paternalistic system of healthcare, with the patients as the passive “recipients” of care, will ultimately inhibit the ability to deliver safe and trusted healthcare.

New expectations of disclosure

Expectations of disclosure now challenge those beliefs and have given rise to a new mindset:

- Disclosure is an ethical obligation, not just a regulatory requirement. The precept of autonomy would require that caregivers not only seek permission to provide specific treatment, but that they give patients (and their families) the array of information needed to make decisions about care. Outcomes of care, including death, require decisions on the part of patients and/or their families.
- Disclosure provides patients – as well as caregivers – the opportunity to recover from the devastating effect of an unanticipated outcome.
- Disclosure, properly managed and controlled, can potentially lessen the frequency and severity of litigation.

- As plaintiff's attorneys often admit, the primary driver of a patient/family consultation regarding suit is not the event itself, but rather the subsequent interactions with the people in the healthcare system.
- Disclosure is seen by some as a fiduciary obligation – i.e., money is paid for a particular result. If a carpenter, plumber or other service worker's effort resulted in an unanticipated outcome, we would expect to be told. Why not in healthcare?
- Finally, the safety of the healthcare system cannot improve if there is a veil of secrecy surrounding what happens in its facilities. The energy that goes to separating caregiver from cared-for impedes the revelation of information that can prevent future events from occurring. Transparency encourages permanent change.

'Effective' vs. 'ineffective' and 'successful' vs. 'unsuccessful disclosure'

“Effective” disclosure provides the patient/family with all information needed for appropriate care decisions. “Ineffective” disclosure does not serve the patient/family because important information is not communicated. However, many people in the healthcare professions talk about “successful” vs. “unsuccessful” disclosure.

Successful disclosure cannot be measured solely on the basis of whether malpractice litigation was dodged. Patients and families, attorneys and risk managers agree there are often genuine compensable needs that must be addressed after some unanticipated outcomes. Actually, *any* effective disclosure is a successful disclosure because it's centered on the issues of patient/family trust, ethical behavior and the caregiver's obligation to the patient. While litigation can be avoided by a sensitive and sincere disclosure, the true measure of successful disclosure is not the avoidance of malpractice litigation.

Effective/Successful disclosure provides patients and families opportunities to:

- Work out issues of distrust with the people inside – not outside – the system.
- Deal directly with their pain so they can heal and get on with their lives.
- Get information needed to make next-step decisions, including the possibility of seeking appropriate compensation.

Effective/Successful disclosure provides physicians, other caregivers and the system the opportunities to:

- Build upon a patient-centered care philosophy and promote openness and transparency.
- Learn from, and not repeat, mistakes.
- Heal psychologically after a mistake or mishap by showing the human face of working in a complex system.
- Show healthcare's humanism to the community at large.

Impact of disclosure on litigation

Few studies have measured the impact of disclosure on litigation and long-term predictions about the ultimate effect of disclosure on litigation cannot be made. However, the following illustrations can be noted:

- After the Lexington, KY, Veterans Administration Hospital realized that its claims experience was increasing dramatically, it began taking the risk of disclosing negative effects of error and unanticipated outcomes(2).
- In 2002, a jury selection research firm conducted a study of a suit that had resulted in a multi-million dollar judgment in favor of the plaintiff. The study consisted of two mock trials in front of two different juries. One version involved the fact pattern as it occurred in the original situation. The other version was identical except for the disclosure of the event to the patient/family. The results were remarkable in the consistency of the identical version to the original judgment. By contrast, the jury in the version where there was disclosure granted an award that was millions of dollars lower. Jury debrief yielded the following observations: Where there was no disclosure, the jury felt the anger of the patient/family and concurred in the belief of conspiracy by the healthcare organization to hide information. The lack of disclosure exacerbated the belief that the organization should be punished for more than compensable real damages. Also, where there was disclosure, members of the jury felt their duty was only to compensate for genuine losses. They expected a disclosure; they were not surprised. However, it affected the equanimity with which they approached the case.(3)

A SKILLS-BASED MODEL FOR DISCLOSURE

In the structure of this disclosure model, a solid presentation of the facts surrounding the event only works when supported by good preparation, a thoughtful initiation of the conversation, a clear conclusion, and proper documentation. Even though the first and fourth skills are not verbal, they do form essential “legs” to keep a “table” (the disclosure conversation) from collapsing.

This model further presumes that each person has areas where he/she will perform more skillfully than others. Consequently, self-evaluation aimed toward improvement is encouraged.

Finally, this model indicates additional considerations to apply to help ensure effective communication.

Disclosure Skill: Preparation

Preparation for a disclosure discussion often is neglected. Circumstances may dictate when and where the communication occurs, so the better prepared the disclosure communicator is, the better chance he/she has of not being caught off guard and making statements that are later found to be erroneous or needlessly inciting.

Review the facts:

- What do we know as fact (about the event) at this point?
- What do we know about any abnormalities following or resulting from treatment?
- What do we know about causation factors?
- When will we know more?

Identify and involve the appropriate participants:

- The attending physician. He/she has the relationship with the patient/family and can explain medical outcomes and next steps.
- Never more than two organizational representatives. More than two can be overwhelming to the patient/family. Whoever accompanies the physician should be someone with excellent interpersonal communication skills.
- Almost never the risk manager at the initial meeting. An exception could be made if the risk manager is the most skilled and effective communicator and is very clear about their role with the patient/family during the meeting. This first encounter is a patient/family-caregiver conversation about something that has occurred during the process of care, not a discussion about money. At second or subsequent meetings, the presence of the risk manager for the purpose of conflict resolution and possible early intervention would be appropriate and effective.

Select an appropriate setting – somewhere private and comfortable and free from interruptions.

Disclosure Skill: Verbal initiation of conversation

The skill of approaching a sensitive conversation is complex. An effective beginning sets the tone for delivering the difficult information.

Ensure that participants from the organization are aware of and sensitive to HIPAA Privacy Rule concerns and desires of the patient.

Discern patient/family readiness and ability to participate. Is the patient conscious or medicated? Is the family tired or so distraught they are unable to process information?

Assess the patient/family's medical literacy and ability to understand:

- Confirm the patient/family's understanding of the course of treatment to date and expected outcomes. This will dictate how to introduce the topic.
- Be sensitive to fact that their beliefs may be contrary to what is considered common medical knowledge.
- Look for evidence of denial regarding the pre-event condition.

Determine the patient/family's level of medical understanding in general.

- Realize that even highly educated people may have medically naïve beliefs.
- Be prepared to gently address questions that appear unrelated to the patient's condition or treatment.
- Remember that many patients/families can iterate medical terms they have heard on television but do not understand.
- Use simple, jargon-free language.

Heart of the discussion: Presenting the facts

If each of these core elements is not covered, it is not possible to say that adequate disclosure has occurred.

MONOGRAPH

- After the patient/family's level of understanding of the medical care and expected outcomes has been established, begin by covering the fact pattern. Simply describe what happened.
- Describe what is known about the outcome of the event at this point. Acknowledge that there will be additional conversations when more is known.
- Describe the next steps to be taken.
 - For treatment of the patient.
 - What the organization is doing to find out how the event occurred. Patients do not want their experience to be repeated. Often the question asked is, "What is the organization doing to find out how the event occurred and prevent it from happening again?(4)
- Sincerely acknowledge the patient/family's suffering. Empathy continues to be controversial among risk managers, lawyers and claims adjusters. Nonetheless, the literature has repeatedly pointed out that patients and families are most disturbed by the perception that the healthcare community is not concerned about the effect of negative events on patients. A well-crafted expression of empathy can both provide the acknowledgment of suffering and the opportunity for both parties to heal.

Texas, California, Florida and Massachusetts have statutes that specifically protect such "benevolent gestures" from being admitted or used as admissions of culpability during litigation. Benevolent gestures are actions taken to communicate compassion or arising from humane feelings when there is no implication as to fault for the outcome.

NOTE: Each organization, working with its attorneys and insurers, must decide if the potential for a benevolent gesture being construed as an admission of culpability outweighs the value of acknowledgement of patient/family suffering. Many would argue that the risk is greater when the patient/family feels that organization and/or caregiver is attempting to avoid blame or, worse yet, is insensitive to the suffering the event has created. Regardless, this is a decision that each organization must determine for itself.

When part of the disclosure discussion, a well-crafted acknowledgement of suffering might start with "I'm sorry ...," "I feel badly ..." or "I'm so sad that" It is more what follows that initial phrase that determines both the efficacy and the interpretation of the apology. Here are some illustrations:

- In the event of a known but unusual complication of a procedure: "*As we discussed in the consent, this is a possible complication of the procedure. I feel so badly that you have experienced it.*"
- In the case of a medical error ("failure of a planned action to be completed as intended or use of a wrong plan to achieve an aim")(5): "*I am so sad that this has happened. You must be terribly upset, and so am I.*"
- After an unanticipated outcome ("any result that differs significantly from what was intended to be the result of a treatment or procedure")(6): "*This is sad and not what any of us expected. I wish it weren't this way and I know you do, too.*"

In an effective acknowledgement of suffering, there should be:

- Sincerity and openness.

- Acknowledgement and expression of sadness and pain the patient/family is having – not about any caregiver’s relationship to the event. If a direct correlation is found between the caregivers’ actions and the patient/family’s suffering, an investigation could be opened. Then the organization can go back to the patient/family, assume responsibility and report actions taken to remedy the situation.
- Separation of our human feelings of concern for the human experience from concerns about ourselves. This is a defining moment in the discussion that will determine whether the patient/family believes their caregiver has their best interest at heart.

Disclosure Skill: Concluding the conversation

- Summarize the fact portion of the discussion.
- Repeat key questions raised by the patient/family.
- Establish a follow-up.
 - Ensure the patient/family knows from whom they will hear next. Are there unanswered questions about compensation, bills or autopsy results? Is the family services department going to contact the family to set up services in the home? Is a risk management representative going to contact them with the result of investigations? Ensure that the involved parties from the organization know about the promise and live up to it. Patient/family trust in the system is already broken. It could be severed by broken promises at this point.
 - Any action the patient/family needs to take should be addressed. *“We need you to call back tomorrow for the results of the test. If I am not available when you call you should...”*
 - Offer to be available for future questions. Give them your business card. Disclosers should make themselves available for future questions. If that’s not possible, the person who will be available to answer questions should be identified to them with a telephone number.
 - Offer the support of other resources: spiritual services, family services, financial services, a place to stay, food to eat, etc.

Disclosure Skill: Documentation

As part of the disclosure process, consideration must be given to what entries, if any, will be made in the medical record. (Any documentation of disclosure should be carefully thought out before its entry, since it will become evidence.) Properly managed, a chart entry will record an objective reflection of what occurred during the disclosure process. Improperly managed, a chart entry could create an impression that the patient and family were not fully informed.

- Describe the event. Documentation should be factual – not an emotional catharsis for the caregiver. Only known facts of the event should be included. Opinions that a particular event caused a specific result do not belong in this record.
- Describe any discussion. If there is a discussion, it should be documented factually, including the list of participants, time and date of the discussion, known facts presented (should be

identical and complete as documented in the chart), without opinions and suppositions and by whom, and next steps discussed (e.g., “*Dr. Smith told the family that Mrs. Jones would be in ICU and would be monitored carefully.*”).

Other vital communication considerations

- Use simple language. Even though the public may be familiar with technical terms healthcare professionals use routinely, their understanding may be incomplete or incorrect. Common terms that may elicit different meanings to patients/families and healthcare providers include: “unanticipated,” “known complication,” “negative test result,” “guarded condition,” etc. It is essential that providers/caregivers step back from their healthcare frame of reference and begin to look at the terms used to explain an event in lay-terms.
- Speak slowly. When humans are in stressful situations, they are unable to process information as rapidly as they can when they are calm. By speaking more slowly, we allow the patient/family to understand both the words and the potential implications of the message.
- Don’t parse the information, but don’t overwhelm the patient/family with enormous amounts of information – the amount of information that a patient/family will retain will be limited due to the emotional context of the discussion.
- Avoid one-sided conversations or monologues. Conversation should be interactive; stop at numerous points to ensure understanding and respond to any questions.
- Be aware of body language. Common wisdom and research has shown that only 35% of the message received is based upon the words we use. A full 65% of our message is interpreted based upon the non-verbal delivery. Non-verbals include rate, tone, timbre, how and where we sit, stand and hold our arms. What we are wearing, and what we do when we speak, can influence how the message is interpreted. Furthermore, aspects of ourselves that we cannot control (gender, ethnicity, age) also shape how our message is received. The goal is for the patient/family to know that we genuinely care and respect them. Actual caring will not help the situation if the recipient is unable to see, hear and feel it in how the message is delivered. Because we tend to be anxious, emotionally upset and worried about the outcome when we participate in a disclosure discussion, it is essential that the discloser be more sensitive than usual about non-verbal behaviors.
- Consider the cultural implications. Not only does the discloser convey messages about his/her beliefs and attitudes through unintentional aspects of communication, but the recipients of the disclosure also bring a wealth of ethnic, generational, religious and socioeconomic variables to the discussion. The healthcare organization should have a complete understanding of the people and populations within the community its facility serves.

All populations are diverse.

- Generational differences can influence beliefs about the role of physicians, nurses, and the healthcare system. They also influence attitudes about “rewards” and “punishments.”

- Religious beliefs can dictate the individual's belief about illness and health and the role of medicine in restoring health. What may seem like an unreasonable decision to a healthcare worker may fit perfectly into the individual's values and belief systems.
- Socioeconomic and educational differences can influence early experiences with healthcare. Depending upon the nature of those experiences, the individual may be positively inclined or negatively inclined toward the system. Furthermore, the understanding of the system may be directly influenced by the ability of the individual to understand his or her role in the healthcare process.

A complete understanding of how generations react to authority figures, how various ethnic groups approach the non-verbal aspects of communication and the religious beliefs that affect reaction to life threatening situations is paramount for a fully effective disclosure process.

Other types of cultural differences emerge in an ethnically diverse population. The organization may wish to study its own cultural makeup to determine whether staff is educated, resources are available and the disclosure policy addresses ethnic considerations. These considerations include:

- Non-verbal implications of communication. A cultural miscue in this area could result in horrible misinterpretation of messages and damage to the patient/family relationship.
- Beliefs about the role of women in authority roles or as physicians.
- Beliefs about preserving the reputation of female patients (e.g., May they be examined gynecologically by a male physician?).
- Beliefs about mechanical and chemical interventions.
- Beliefs about death and permanent injury.

Maintain a neutral tone with the patient/family. Although you may believe differently, the disclosure discussion is not the time to convince them. The role of the discloser is to acknowledge the beliefs of the patient/family.

Manage patient/family emotions. Management of these emotions can provide a strong non-verbal communication of sincerity and genuine caring. The most common reactions to bad news are denial, anger and crying.

- Some patients may take longer than others to accept the news and may deny the implications of the event or generate excuses for the event. (*"My mother had cancer; I probably had to lose that breast someday."* *"I know it's hard to operate on a heavy person."*). Although it is tempting to concur, this can be just a temporary emotional coping mechanism. Anger may emerge later when the patient/family member speaks about the event to someone else who may point out some discrepancies. The discloser should gently bring the recipient back to the reality of the facts and ensure that, at a minimum, everyone understands the nature of the injury.
- Anger often is directed at the bearer of bad news. Because anger is perceived as dangerous, the discloser's first reaction in an angry encounter may be defensive. Except when physical harm seems imminent, allow the patient/family to vent. Acknowledge how frustrating the situation must be and that feelings of helplessness and anger are understandable. Nonetheless, it is permissible to point out that blame is premature until an investigation is completed.
- Crying makes many feel helpless to a grieving person. In addition, there is a feeling that crying is a private activity that should not be witnessed by others. In a disclosure

situation, the needs of the recipient must drive the situation. By sitting patiently and acknowledging the appropriateness of crying, disclosers can convey sensitivity to the painful nature of the discussion.

SETTINGS WITH UNIQUE IMPLICATIONS

Effective communication is not a “one size fits all” skill. Special settings will elicit certain types of psychological and legal quandaries for which the organization must be prepared. The examples below illustrate the variability that needs to be considered when working with certain populations.

Pediatric

When the lives of small children are involved, disclosure can be particularly emotion-laden. Considerations should be given to:

- Whether to involve the child in the discussion. What is the age of the child? What is their ability to comprehend the situation? What is the nature of the information? Was the child involved in the consent process for treatment? Is there psychological support (therapy) available to help a child who may have participated in the decision to have treatment and now may be suffering unanticipated negative consequences?
- How to manage disclosure when there are issues of non-custodial parents. What are their legal rights? What is the relationship between parents and the facility?
- How to manage disclosure when the child is the ward of the state. Is your policy clear about to whom disclosure should be made? What information are the parents entitled to?

Special needs

When the recipient of the disclosure has hearing, speech or language barriers, clinically recognized mental or emotional limitations, or is a minor (e.g., young parent), the organization should pay special attention to preparation for the meeting.

Ideally, preparation should include a meeting of interdisciplinary experts to advise on wording and support services appropriate to the needs of the recipient. Depending upon that need, interpreters or behavioral health staff may be appropriate participants in the disclosure discussion. Every organization should be aware of its more common special need populations and have strategies to address those needs.

Post-acute care

Long-term care and home health settings bring their own set of issues and considerations. Often disclosure may be made to a family member. Family emotions are as fragile when the patient is elderly or chronically ill. Feelings of guilt about level of involvement with care or past family disagreements often are reflected in responses to issues or outcomes of treatment. Frailty and overall poor health status do not detract from the trauma of an unanticipated outcome.

In addition to falls and medication errors, issues such as elopement, assault by other patients and allegations of staff abuse and neglect are faced in long-term care settings. These incidents are

often also reportable to the state and carry implications beyond those of potential litigation. It is important that families know exactly to whom disclosure of the event is being made in addition to themselves.

WHO IS TAKING CARE OF THE DISCLOSER?

One area related to disclosure that is often overlooked is the effect of an unanticipated outcome on caregivers involved in the event.

Feelings of sadness, failure to heal and guilt can erode their self-esteem as healers and drain their emotional stamina. Fear of litigation can constrict emotional openness. Moreover, physicians have reported they found little support after such an event(7).

It is essential for healthcare leaders to recognize that an unanticipated outcome requires humane support of all individuals involved – the caregivers as well as the patient and family. Ignoring the trauma for those within the healthcare family eventually can create a situation where humans develop the coping mechanisms of psychological distancing, which is the opposite of what is desired in caregivers.

Debriefing sessions, private support counseling, acknowledgement of the team's experience and ongoing support are only a few of the ways healthcare organizations can support their front-line workers.

SUMMARY AND CONCLUSION

This three-part series on disclosure of unanticipated outcomes in healthcare is intended to provide an overview of the current thinking about disclosure and steps the organization can take to develop an approach to disclosure that is comprehensive and supportive of the needs of patients, families and providers. What should be apparent is that disclosure is not simply a requirement – it is a philosophy and part of a comprehensive approach to patient/family communication.

'The conversation table'

Disclosers who do their job well are able to see a conversation as a table supported by four legs: good preparation, a thoughtful initiation of the conversation, a clear conclusion and documentation supporting the heart of the discussion. Proper documentation comprises a factual presentation of the facts of the event, the known outcomes of the event, an investigation intended to prevent future events and a statement of concern and empathy.

Effective disclosers are sensitive. They consider the readiness and ability of the recipient to learn what happened. Information is provided clearly with non-verbal techniques conveying openness and sincerity. The diversity of the facility's community is acknowledged and accommodated. The

special conditions and psychological implications of unanticipated outcomes within specific patient populations and settings are understood.

Aside from expectations of individuals, there must be commitment by the entire organization to effective disclosure. This can be achieved by building and maintaining:

- Disclosure policies into a comprehensive communication approach with patients and families to encourage honest communication and incorporate patients into the decision-making process for every aspect of care.
- A culture that sets the expectation that transparency will be the norm, not the exception in all communication among members of the organization's physician and non-physician staff as well as between staff and patients/families.
- Systems within the organization that provide training and coaching for any staff who may be involved in breaking bad news of any type to a patient or family member.
- Post-event support systems for patients/families and for caregivers and all affected staff.

If our healthcare system can succeed in making effective communication the norm, we will advance light years in our effort to reduce errors and change the punitive nature of malpractice judgments. Safe and trusted healthcare can only be achieved one organization, one provider and one patient at a time.

REFERENCES

1. Institute of Medicine. *Crossing the quality chasm: A new health system for the 21st century*. Washington, D.C.: National Academies Press, 2001.
2. Kraman, S.S., Hamm, G. Risk management: extreme honesty may be the best policy. *Ann Intern Med*. 1999; 131(23):963-67.
3. Popp, P.L. How will disclosure affect future litigation? *ASHRM Journal of Healthcare Risk Management*. 2003; Vol. 23 No. 1: 5-9.
4. Vincent C., Young, M., Phillips, A. Why do people sue doctors? A study of patients and relatives taking legal action. *Lancet*. 1994; 343(1): 609-13.
5. Institute of Medicine. *To err is human: Building a safer health system*. Washington, D.C.: National Academies Press, 1999.
6. Joint Commission on Accreditation of Healthcare Organizations. *Comprehensive Accreditation Manual for Hospitals: The Official Handbook*. Oakbrook Terrace, IL; Joint Commission on Accreditation of Healthcare Organizations, 2001. RI. 1.2.2.
7. Gallagher, T.H. et al. Patients' and physicians attitudes regarding the disclosure of medical errors. *JAMA*. 2003; 289(8): 1001-1007.

ADDITIONAL RESOURCES

The Risk Management Handbook for Healthcare Organizations. San Francisco: Jossey-Bass.
www.ashrm.org/store or call (800) AHA-2626.

Risk Management Pearls on Disclosure of Adverse Events. Chicago: ASHRM.
www.ashrm.org/store or call (800) AHA-2626.

ACKNOWLEDGMENTS

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