



AMERICAN  
SOCIETY FOR  
HEALTHCARE  
RISK  
MANAGEMENT

# 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](http://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.

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- 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.

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### ADDITIONAL RESOURCES

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

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

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