The Patient and Family Experience

II. COMMUNICATING WITH THE PATIENT AND FAMILY

Prompt, compassionate, and honest communication with the patient and family following an incident is essential. Unfortunately, this is the one aspect of the response to an incident that is most often managed poorly.

Because of the emotional effects of these events on both the patients and the caregivers, communication can be difficult for all parties. Communication failures compound the injury for the patient, as well as for the caregivers, and are thought by some to be the major reason patients file malpractice suits.

Consideration of this complex subject is divided into three sections:

A. Initial Communication: **What** is communicated and **when** it should be done

B. Initial Communication: **Who** provides the information and **how** they do it

C. Follow-up communication while in the hospital

Communication and follow-through after discharge are considered in Section IV.

A. Initial Communication: What and When

The patient and/or family should be fully and promptly informed of any incident—that is, any adverse event or serious error that reaches the patient. There is general agreement among patients and caregivers that it is not appropriate to inform patients of minor (harmless) errors. Near misses, errors that could have caused harm but were intercepted, are a special case and responses need to be individualized. Caregivers and administrators need to discuss and agree on the threshold for informing and the rationale for choosing that threshold. This can be a difficult task, but consistency requires a clear institutional policy.

The occurrence of an incident should be communicated to the patient as soon as it is recognized and the patient is ready physically and psychologically to receive this information. Typically, this should occur within 24 hours after the event is discovered. Early acknowledgement is essential to maintaining trust. If it is not possible to communicate with the patient, the initial communications should begin with those members of family or health-care proxy who will be representing the patient in further discussions.

Initial explanations should focus on what happened and how it will affect the patient, including immediate effects and the prognosis. The caregiver should acknowledge the event, express regret, and explain what happened. If an obvious error has been made, the caregiver should admit it, take responsibility for it, apologize, and express a commitment to finding out why it occurred.

The caregiver should also explain what is being done to mitigate the effects of the injury. Explanation of how or why the event occurred should be deferred until the investigation is completed. However, the caregiver should inform the patient and family that the causes of the event are being investigated and that information will be shared with them as soon as it is available.

Reasoning and Evidence

Communication about incidents to patients and families is a crucial part of the institution's response to adverse events. Open, honest communication is essential to maintaining and restoring trust, and to providing appropriate ongoing care. It is not difficult to preserve trust when times are good—when there have been no problems in the delivery of care. The real test is preserving the relationship when something has happened that may strain it. How the communication process is handled profoundly influences the reactions of patients and their families.

Even in the absence of adverse events, many patients feel vulnerable by virtue of their being ill or requiring medical care. Thus, when adverse events do occur, patients may have particularly severe or complex emotional reactions. Fear, anxiety, depression, anger, frustration, loss of trust, and feelings of isolation are common reactions.[5,6] And after particularly traumatic and life-threatening events, intrusive memories, emotional numbness, and flashbacks are possible.[6] These reactions may occur even when the event was not due to an error and even when the possibility of it occurring was discussed during the consent process.

Moreover, the patient-physician or patient-nurse relationship often becomes complicated in the aftermath of an adverse event when it is due to an error. Patients are unintentionally harmed by the very people whom they entrusted to help them. And, subsequent to the adverse event, they are often cared for by the same clinicians who were involved in the injury itself. Even when caregivers are sympathetic, supportive, and open, patients are likely to experience conflicting emotions about their caregivers.[6]

The reactions of patients and their families to incidents are influenced both by the incident itself and the manner in which the incident is handled.[5,7] Inadequate or insensitive management may cause further emotional trauma, while open acknowledgement of the injury, sensitivity, good communication, and skillful management of corrective actions may reduce emotional trauma.[5,7]

Data in the medical literature suggest that most patients wish to be informed of adverse events. In a survey conducted among 149 patients from a U.S. academic internal medicine outpatient clinic,[8] patients responded to three medical error scenarios (minor, moderate, and severe). Ninety-eight percent wanted some acknowledgment of errors, even if minor. For both moderate and severe errors, patients were significantly more likely to consider litigation if the physician did not disclose the error.

In one British survey, 92% of patients believed that a patient should always be told if a complication has occurred, and 81% of patients believed that a patient should not only be informed of a complication but also be given detailed information on possible adverse outcomes.[9] In a British survey of 227 patients and relatives who were taking legal action in malpractice cases, plaintiffs wanted greater honesty, an appreciation of the severity of the trauma they had suffered, and assurances that lessons had been learned from their experiences.[7]

When they are injured by physicians' mistakes, patients may feel hurt, betrayed, devalued, humiliated, and afraid. By taking responsibility and apologizing, the physician acknowledges these feelings, shows an understanding of their impact, and begins to make amends. The apology helps to restore the patient's dignity and begin the healing process. It also helps the physician deal with his own emotional trauma. On the other hand, failing to admit error and express regret "adds insult to injury" by not fully respecting the patient's situation.

Open communication by individual clinicians and risk managers should be strongly supported by institutional leaders with clearly stated and agreed-upon policies and directives. It is difficult for a clinician to be honest and open about problems that have occurred if he or she is not supported by senior management.

Recommendations

Caregivers should promptly inform the patient and/or family about any adverse event or error that reached the patient even if no harm was done. Minor errors that do not reach the patient do not need to be disclosed. Discussion of near misses, serious errors that were intercepted, should be individualized. If the patient is aware of the error, or if knowledge of it can help prevent a recurrence, the patient should be informed. When in doubt about whether communication is called for, a caregiver should consult an internal expert, such as the risk manager, safety leader or senior administrator.

ieneral Principles Regarding lisclosure in the Immediate ftermath of an Incident:[11]

teport only the facts of the ncident – what occurred, not ow or why you believe the utcome occurred.

)isclose reliable information n timely fashion as it becomes vailable.

:xplain your recommendations or further diagnostics and herapeutics.

:xplain the implications for rognosis.

Caregivers should be honest and open about the incident and about what is being done to mitigate the injury and to prevent a recurrence. Honest communication conveys respect for the patient. Failure to acknowledge the event can be very distressing for the patient and is a powerful stimulus to complaint or litigation.

If the event was clearly not caused by an error (i.e., a Type 1 or 2 unpreventable adverse event), or the cause is unknown, the caregiver should express regret (We're sorry this happened to you.), explain what happened and discuss what will be done to mitigate further harm. It is important to make sure the patient understands that the injury is not the result of a failure of care, but an inherent risk. This is relatively easy when the risk of complications is high and well-known to the patient, as in chemotherapy (Type 1).

For less common unpreventable events (Type 2), even when full attention has been given to obtaining informed consent, the patient's initial reaction is often to assume that someone made an error. Therefore, it is important to provide a full and patient explanation about what happened, even when it seems very straightforward to the caregiver. It is very important for the patient to perceive that the staff take the injury seriously and are sorry that it happened, but also to understand that preventing it was not under their control.

If it is not clear whether an injury was due to an error, the event still should be acknowledged and regret should be expressed as above. However, it is important not to jump to conclusions, to blame oneself or another, nor to take responsibility for an event, before all the facts are known. A full investigation should be promised, together with a commitment to report back to the patient when more is known.

When an event is caused by an error or other type of systems failure (preventable adverse events Types 1–3), a fuller explanation is indicated, as well as an apology and explanation of what will be done to prevent recurrence in future patients. Regardless of who made the error or what system failed, the major responsibility for communication with the patient falls on the attending physician who is responsible for the patient's care.

There are four essential steps in the full communication of preventable adverse events:

1. Tell the patient and family what happened. Tell *what* happened now; leave details of *how* and *why* for later.[10] Determining the causes of an adverse event requires careful analysis and is time-consuming. However, patients and their families are likely to want immediate answers. Therefore, early after an adverse event, limit discussions to known facts and avoid speculation. Speculation and preliminary conclusions are often interpreted by patients and families as definitive. The nature of incident investigations is such that early impressions are frequently contradicted by subsequent, careful analysis. If speculative information is shared with patients and

families and later contradicted by the results of careful analysis, clinicians are forced to correct themselves, which may cast doubt on their credibility and the credibility of future information. The conclusions of the adverse event analysis and the system changes recommended to prevent future adverse events should be discussed with the patient and family later when this information becomes available. On the other hand, withholding available information that the patient must know immediately is inappropriate.

2. Take responsibility. Whether or not the incident resulted from a specific act, the attending physician should make a statement of responsibility to the patient and/or family. Taking responsibility for an adverse event is an essential step in the full communication of an event. As the person the patient entrusts their care to, the attending physician must assume responsibility even when he/she did not actually make the mistake that caused the injury. The overall responsibility and accountability for an adverse event rests with the hospital. Thus, following a serious event it is incumbent upon the organization and its leaders to also accept responsibility and communicate that responsibility and remorse to the patient and family. Because every event is unique, organizational leaders and clinicians should coordinate communications with the patient and family.

On first consideration, it may seem odd that in situations where the physician had nothing to do with an adverse event, s/he should take responsibility for it. In this circumstance, taking responsibility does not mean assuming sole culpability for the adverse event. A host of factors likely contributed to the adverse event—many of them beyond any one person's control. However, as the leader of the team, the physician is an integral part of the clinical system that delivers care to the patient in question. S/he is, understandably, the person who the patient and family assume is responsible for the care. Patients look to their physician for care and comfort, and to make things work for them. The patient wants to know that someone is in charge and has control over the situation.

4 Steps to Full Communicatio

Tell the patient and family what happened.

Take responsibility.

Apologize.

Explain what will be done to prevent future events.

In assuming responsibility for the event, the physician and the hospital leaders accept responsibility for future action: trying to find out the causes of the event, informing and updating the patient and family, and monitoring and managing any complications of the adverse event. They communicate the institution's responsibility to do whatever possible to improve systems to prevent future similar events from happening to other patients.

If the physician was directly involved in the adverse event, he/she should take responsibility for his/her own role, but also explain the contributing systems factors that made the adverse event more likely. However, he/she should not blame "the system" or use such terms as "systems thinking" as an excuse to avoid responsibility.

There are several ways to say this:

- "We failed you."
- "This shouldn't have happened."
- "Our systems broke down. We're going to find out what happened and do everything we can to see to it that it doesn't happen again."
- "I'll let you know what we find as soon as I know."

3. Apologize. When there has been an error, one of the most powerful things a caregiver can do to heal the patient—and him/herself—is to apologize. Apologizing is an essential aspect of taking responsibility for an injury, even if, as is common, several systems failures are responsible for the error rather than one person. Explaining the event, communicating remorse, and making a gesture of reconciliation can do much to defuse the hurt and anger that follows an injury.[11]

Immediately after an event, the primary caregiver should express regret for what happened—even if

the causes of the event are not all known. Patients are likely to feel hurt and vulnerable after an event, and the expression of empathy and compassion is an essential, humane response to an adverse event, regardless of its cause. ("*I'm sorry this happened. It's terrible.*")

If an obvious error has occurred, whoever made the error should disclose it promptly, apologize, and communicate his or her commitment to finding the reasons for the error ("*We made this error. I apologize.*") Although errors by individuals usually result from systems failures (which need to be identified and addressed), few patients understand that. They hold the individual responsible. As a result, it is immensely valuable for the person who made the error to apologize and show genuine remorse. However, consideration must be given to the caregiver's ability at the time to emotionally handle the situation. If the caregiver is unable to adequately communicate with the patient, it may be desirable to have another party step in.

The attending physician should also apologize if the error was made by someone else. In these cases, it may be wise to make the apology a joint effort, i.e., for the person who made the mistake (resident, nurse, radiologist, etc.) to meet with the patient together with the attending for the apology.

Contrary to what many physicians believe, there is little evidence that apologizing increases the risk of a malpractice suit.[12] In fact, experience in malpractice cases indicates just the opposite: that the failure to communicate openly, take responsibility, and apologize contributes to patients' anger. Some malpractice lawyers contend that two-thirds of malpractice suits stem from a failure to take responsibility, apologize, and communicate openly.[13]

4. Explain what will be done to prevent future events. Once the investigation is completed and corrective changes are planned, it is important to inform the patient and family of these plans. Injured patients have a strong interest in seeing to it that what happened to them does not happen to someone else. Caregivers often underestimate the importance of this aspect of the response to an event. Knowing that changes were made and that some good came of their experience helps the patient and family cope with their pain or loss. It gives a positive meaning to their experience to know that their suffering is not in vain.

B. Initial Communication: Who and How

A serious incident represents a major threat to the patient's sense of control and trust in the caregiver. Thus, it is essential that the communication be from a person with whom they have a trusting relationship, and that it convey care, concern, and control over the patient's care. Because the purpose of these discussions is to support and inform the patient, they should be held in private, in a manner that empowers the patient and avoids the barriers or demonstration of rank that may intimidate or discourage them.

In the usual situation, the physician responsible for the patient's care is the person most suitable to make the apology. However, in some situations, other health care professionals or administrators may be more appropriate for disclosing the error and apologizing. These individuals may include a nurse who made the error or another staff member who has an existing relationship with the patient and family. If the clinician responsible for apologizing is absent or emotionally unable to do so, other trained individuals, such as a hospital vice president or senior clinical leader, should substitute. An ombudsman/mediator can play a valuable role in these situations.

Subsequent discussions with the patient and family may be appropriately held by the attending physician or by leadership personnel. Under special circumstances, members of the quality and safety reviewing team may be involved. In all cases, staff should be adequately and appropriately prepared, both as to the content and style of the communication. All such discussions should be conducted with the patient's concerns primarily in mind, and in private, to make the patient and family most comfortable.

Reasoning and Evidence

When the same physician is responsible for care before and after the event, this is clearly the person to assume this role. When the site of care is different (as in transfer to an ICU), it is appropriate for caregivers from both settings to be present and conduct the discussion together.

Ensuring coherence and consistency of communication requires that subsequent discussions be conducted by whoever will address the patient's concerns most knowledgably. In many cases, this will continue to be the attending physician. However, information about improvement efforts or institutional responsibility may more appropriately be provided by leaders in these areas.

Who and How to Communicat

A trusted caregiver should lead initial communication.

The person responsible for next steps in care should lead subsequent communication.

Include patient's primary nurse in communications.

Provide staff with coaching in communication techniques.

Choose a quiet, private area for communication.

Recommendations

1. The initial communication should be by or at least in the presence of a caregiver with a prior relation of trust with the patient. Ideally, this will be the attending physician or the physician who planned and carried out the treatment.

2. At the same time, to define the next steps in care, it is also often helpful to the patient and family to have present the person most responsible for those steps. If this is someone different from the primary caregiver, e.g., the ambulatory patient wakes up in an ICU, the physician now responsible for their care should also be present to assure them (patient and family) of the commitment to continue to provide care. If the discussion is anticipated to be complex or difficult, the patient should be encouraged to have another person available or present to provide support.

3. It may also be helpful to have the patient's primary nurse present, to participate, observe, and support. It is not recommended at this initial stage that a higher-level administrator participate, except in the most catastrophic situations. Similarly, including someone identified as a "risk manager" in these first discussions can set the wrong tone.

4. Discussion with patients and families under these circumstances may be difficult, and not all physicians and nurses will be comfortable and capable of doing this. When the appropriate staff are anticipated to have difficulty, or are apprehensive themselves, someone with experience and competence in this area should accompany or coach them

ahead of time. Institutions need to develop training in these techniques and make sure all staff are aware of sources of assistance for these discussions.

5. The choice of the setting for communicating incidents is important, particularly if apology or restitution is appropriate. When possible, the meeting should be prescheduled, and arranged in a private and quiet area that supports both confidentiality and the feelings of the patient and family. A single room in the hospital is ideal, as is a private office for ambulatory communications. A visit to the patient's home may be indicated if the patient has been treated in a clinic or has been discharged. A double room, or any open space, such as a hallway or waiting room in the ambulatory arena should never be used. Moreover, it is not appropriate to summon the patient and family to an executive suite.

C. Follow-up Communication

One or more subsequent discussions are always indicated following a serious event. In addition to continuing to show support and concern, and identifying further opportunity for amelioration, the primary purpose of follow-up communication is to provide fuller description of the events that occurred and the nature of systems changes that have been identified to address them. This discussion should be open-ended, and not limited by time or interruptions.

Follow-up Communication

Conduct follow-up sessions promptly.

Primary physician or team members should lead sessions.

Involve CMO or CEO in serious or difficult cases.

Recommendations

1. Follow-up sessions should be arranged as soon as significant additional information is available. If delay is encountered, the patient or family should be frequently apprised of the situation, with apology for the delay.

2. The attending physician and team members may conduct these follow-up meetings as appropriate.

3. In especially serious or highly charged cases, higher officials in administration, including the CMO or even the CEO, should be involved. Senior administrative involvement is especially indicated if faith in the primary caregiver has been compromised or he/she has not been fully successful in communicating.