Should We Tell Parents When We've Made an Error?

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abstract

One of the most difficult experiences for any doctor or nurse is when they realize that they have made a mistake that has harmed a patient. In the past, mistakes were seldom disclosed to patients. The prevailing ethos was one of professional silence, secrecy, and shame. That has begun to change. Many professional organizations in both medicine and health law recommend full disclosure of mistakes and apologies for the harm that is caused. An atmosphere of openness and honesty leads to a culture of quality and safety. In this Ethics Rounds, we analyze the complex emotional and ethical issues that arise when doctors recognize that an error has occurred.

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THE CASE

SP is a 4-month-old former 23-week preterm infant. She was extremely unstable for the first several months of her life, requiring weeks of high-frequency oscillating ventilation and vasopressor infusions. She had multiple operations for complications of necrotizing enterocolitis. Her mother had been told on numerous occasions that she would die. Doctors recommended a do-not-resuscitate order. SP's mother did not agree with the recommendation for a do-not-resuscitate order.

At 4 months of age, SP was improving. She was weaning from conventional mechanical ventilation and tolerating small amounts of tube feeding.

One weekend, SP began acting unwell. The medical team evaluated her for sepsis and started antibiotics. SP continued to worsen, and eventually was placed back on high-frequency ventilation and multiple vasoactive infusions. These did not help. SP went into cardiac arrest.

A radiologist noted, on a chest radiograph taken during the resuscitation, that SP's central line was in her aorta and not in a central vein as it should have been. Review of previous radiographs showed that the line had been malpositioned this way since its initial placement many weeks earlier.

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SP's decline over the past several days and her cardiac arrest were likely the result of arterial emboli from her central line and the administration of medications directly into her arterial system.

Although the team was able to restore SP's vital signs, she was severely neurologically injured. Both her clinical examination and MRIs were consistent with severe hypoxic ischemic injury.

The clinicians consult the ethics committee to ask 2 questions:

1. *How much should they tell SP's mother about the misplaced central line?*
2. *Is it acceptable for doctors to suggest the withdrawal of life support when SP's condition is the result of a medical error?*

SIGALL K. BELL, MD, AND ROBERT D. TRUOG, MD, COMMENT:

Disclosure of medical error has rapidly gained national attention, but clinicians continue to struggle with what to say to harmed patients and their loved ones. Sometimes it is not clear whether an error occurred, but in this case there seems to have been a clear-cut error: a missed chest radiograph finding showing a malpositioned central line weeks before the patient's decline. Had this finding been appreciated at the time, the line placement could have been corrected, likely averting the acute downstream complications.

Some might wonder whether informing the mother about the error is ethically sound in cases like this, given the infant's poor prognosis. They may debate whom the disclosure is really serving in such a setting. Is nondisclosure justified in cases of death or imminent death, if providing the information only harms the family by increasing their grief and anger? The ethical principle of "therapeutic privilege," sometimes referred to as "benevolent deception," has historically been invoked to justify nondisclosure of information when clinicians have strong evidence that such disclosure would lead to more harm than good.[2,3] We know, however, that patients and families almost always want an honest account of the facts, even when clinicians believe that it may be too difficult for them to hear.[4,5] Today's professional norms, therefore, require openness and transparency in all but extremely rare circumstances, highlighting that "patients have a right…to be free of any mistaken beliefs about their care."[6,7]

An early step in preparing for the ideal disclosure process is to inform all the interprofessional providers involved in the error, and to glean their perspectives on the event. The difficulties of connecting with current providers and with those from weeks past, as well as the oft-underappreciated challenges of telling other providers of their mistakes,[8] often proves overwhelming to accomplish this task at the frontlines of care. As a result, the initial radiologist or the clinician who placed the line may not even learn of the subsequent events, a real "miss" from the learning and accountability standpoint. Circling back to all involved providers also can help fill any gaps in the story, better inform the disclosure, and signal respect for all team members.

The next consideration is deciding who should disclose the error to the mother. The clinician who initially placed the central line? The radiologist who missed the first chest x-ray finding? The radiologist who discovered the mistake? The current attending? And should risk managers, nurses, administrators, and/or organizational leaders also be considered? Today, programs emphasize an interprofessional team approach, potentially including radiologists or other specialists and interprofessional team members in the disclosure conversation.[9,10] The presence of an institutional leader also can signal to the patient and family that the issue is being taken seriously. But this inclusiveness must be balanced against the importance of not overwhelming the family, and the potential time lag for reaching or coordinating providers. In a complex case like this one, where trust between the mother and the team already may be fractured, the scale likely tips in favor of a smaller initial conversation, including someone with a close therapeutic relationship to the mother.

Should the team recommend cessation of life support? Although we cannot know how this infant would have fared had the error not occurred, it is certainly possible that she could have done reasonably well. Given the mother's previous refusal to consider limitations in life support, and the fact that the infant may have continued to improve if the error had not occurred, some might argue that the clinicians are obligated to continue treatment. Although this view is commonly held by many clinicians, it mistakenly prioritizes the clinicians' guilt and concerns about their potential responsibility for the outcome over decisions that are based on the best interests of the patient. Simply put, what matters for the patient is the clinical reality of the situation, not the path by which that reality came to be. As such, the advice and recommendations of the clinical team to the mother should be same as would be given to the parents of any infant with this condition, regardless of whether an error occurred.[11,12]

This being said, it may be psychologically difficult, even impossible, for those who believe they were implicit in the error to counsel the mother in this way. Here a division of labor may be helpful, so that clinicians who were not involved in the error could engage in decision-making with the mother without the overlay of guilt and regret that could distort the conversation.

Providing support for all the involved clinicians is crucial. Although patients and family members are clearly at the sharp end of errors, such experiences also can have devastating effects on providers.[13–16] The clinicians may have their own desire to speak with the mother and apologize for their role, and such an opportunity may be helpful in their process of self-forgiveness. Because disclosure is best viewed as a process rather than an event, future opportunity for others to talk with her, if she is interested, may follow.

Ensuring longitudinal support for patients and families when they learn of errors is critical, especially when they may be overwhelmed by the immediate emotions of caring for a harmed loved one. Facing an enormous decision about the care of her child, this mother may need time and guidance to sort a likely array of anger, grief, confusion, helplessness, isolation, and guilt, among other common reactions to medical error.[17] Equally important, family members should have a chance to share their own perspectives about what happened. Seeking patient and family views signals that their input is valued, provides additional information that may have been missed by clinicians, and offers an opportunity for harmed patients and families to contribute to institutional learning.

In short, the team should disclose the error to the mother. Although the initial disclosure conversation is likely best led by a small group who can represent the views of the team and the hospital, all the involved clinicians should be part of postevent learning. Although the acute decompensation was likely caused by the malpositioned line and the missed chest x-ray finding, the team should still guide the mother as they would if the infant's condition were the result of the natural course of the illness rather than a medical error. Given the magnitude of emotion and hardship faced by both family and providers in challenging scenarios like this one, longitudinal support for everyone involved is key to promoting healing.

KEITH J. MANN, MD, COMMENTS:

The Institute of Healthcare Improvement estimates that 40 000 instances of medical harm occur in US hospitals each day.[18] Although many of these events are minor, they still erode the trust that patients and families have in the health care system. These events have a profound impact on patients, families, health care providers and organizations, and even on whole communities.

Numerous professional organizations, including the Institute of Medicine,[19] The Joint Commission,[20] and the American Society for Healthcare Risk Management,[21] recommend full disclosure when a medical error occurs. And health care providers themselves generally agree, in theory, that patients and families have the right to know when a medical error occurs. Thus, in this case, SP's mother absolutely has the right to know that the misplaced central line likely caused the arterial emboli and medications inserted via that line likely contributed to the patient's cardiopulmonary arrest.

In spite of the general agreement that disclosure is the right thing to do, physicians often fail to disclose medical errors.[22] Patients and families are often dissatisfied with the quality of the disclosure.[23] Why is this?

When the generic patient, about whom everyone agrees, becomes a specific newborn in your hospital, and when the nurse caring for that patient has served the hospital tirelessly for 20 years, or when the physician overseeing the care is a close colleague, then the conversation can take on a different tone. Emotions such as uncertainty and fear enter the equation and can lead people to make choices that subvert the ethically correct response.

Furthermore, in the real world, there are many factors that weigh on both the decision of whether to disclose and on the tone, structure, and content of the actual disclosure conversation itself. These factors often lead to discussions that fall short of full and honest disclosure of medical errors. The factors include the fear and concern of litigation, negative impact on professional reputation, loss of privileges or license, and concern over the ability to effectively disclose the error to the family. They also sometimes include uncertainty regarding the details of the event itself. Such uncertainty can play a significant role. In the case presented here, there is some uncertainty as to whether SP's decline in the days before her cardiac arrest was due to arterial emboli from her central line, from the administration of medications directly into her arterial system, or from other factors. There is also uncertainty about who should take responsibility for the error.

Serious, unexpected events may or may not be due to a deviation in accepted performance standards. Even when there is a deviation from an accepted performance standard, the patient outcome may be unrelated to the actual safety event. Causality is often difficult to determine immediately after an event. Disclosure can be affected by the certainty or uncertainty surrounding the perceived error and its impact on the patient. Disclosing an event in which there is a clear error, and a clear link between the error and the outcome, is different from discussing an event with a family when there is still uncertainty.

Although all of these factors should be considered in the conversation with the family, they should never be a reason not to have a conversation at all.

Perhaps the most ambiguous sort of error is an error in diagnosis. Unlike

medication errors (ie, a 10-fold dose of medication is given to the patient) or surgical errors (ie, a retained surgical instrument), diagnostic errors are often less obvious and more easily ignored. When a diagnosis is missed, it is hard to know whether one should have been able to make that diagnosis. Things are always clearer in retrospect. A missed diagnosis can lead to a very uncomfortable conversation, as when families ask, "How did Dr X not realize my son had meningitis?"

Diagnostic errors continue to be associated with a more traditional, individual assignment of blame when contrasted with the advances in a system-level understanding of other medical errors. Recently, experts in the field have focused on better understanding the cognitive biases behind the decisions we make and emphasized the importance of misdiagnosis-related harm (ie, understanding the harm from the event and the context within which that harm occurred).[24] This paradigm shift can help ensure this underemphasized source of patient harm is better understood and the same systems approaches we take to medication errors can be applied to harm related to a misdiagnosis.

Errors occur in every health care system and in all settings. It is critically important to have a consistent approach to identifying, mitigating, and understanding these errors and approaching patients, families, and staff when an error does occur. Such a plan must be supported and embraced by both executive leaders and the board of directors.

Many organizations have such plans. They have moved away from the traditional "deny-and-defend" approach to error. Instead, they advocate and practice a more open and honest disclosure of medical errors to families. There are many reasons for this shift. It leads to improved trust from families.[25] When done effectively and coupled with an effective claims management model, it may lead to fewer lawsuits and overall less of a financial burden on hospitals.[26] When coupled with quality improvement efforts, it leads to better patient care. Early detection of errors and honest disclosure forces an organization to fully understand the event and identify areas for focused improvement efforts.

How does it work in practice? A common approach is to begin with a conversation with the family immediately after an unexpected event. This can take place even if there is not a clear understanding of what exactly happened. This immediate conversation should include empathy toward the family for the event that happened, a commitment to understanding more, and a promise to stay in touch with the family and to discuss what is learned. Immediate patient care needs and support for the health care team involved in the event are also prioritized at this time. The immediacy of the conversation helps avoid any appearance of incomplete sharing of information. It also can lessen the family's concern that the cause of a bad outcome isn't known. Uncertainly always exists initially; patients and families don't expect immediate answers. This initial conversation allows trust to develop between the organization and the family that is affected by the event, allowing future conversations to unfold more easily.

In this case, SP's mother should be told that the central line was misplaced and that the clinical team believes there is a connection between the misplaced line and SP's clinical deterioration over the past few days. The doctors should apologize for the misplaced line and for the fact that they didn't recognize it earlier. They should express a commitment to better understanding what happened. Finally, they should promise the family that they will keep the family updated as they learn more. The parents should be given a contact number and a person to go to with further questions.

Hopefully the trust earned will allow the health care team to continue with the difficult discussions around end-of-life care. The fact that an error occurred does not negate the need for these important discussions and should not influence the nature of how these are approached with the family.

JOHN D. LANTOS, MD, COMMENTS:

Medical culture has changed dramatically over just a few decades with regard to the disclosure of errors. Thirty years ago, Jay Katz admonished doctors for not talking to patients about risks, benefits, and options for treatment. His book, *The Silent World of Doctor and Patient*, does not even mention mistakes.[27] Around the same time, Charles Bosk wrote an entire book about the errors that surgical residents make.[28] He discusses in great detail how supervisors deal with the mistakes that trainees make. But his book, too, suggests (by complete omission of any mention) that these mistakes were never disclosed to patients and their families. Today, there is universal agreement, at least in theory, that we must tell patients and families about mistakes. The reason such disclosure often does not occur is not because, today, there is any serious moral argument about whether it is the right thing to do. Instead, today, when disclosure does not occur, it is simply because such disclosure is psychologically difficult for doctors to do. But there are ways to learn. There are skills and techniques. It is both an individual and an institutional moral responsibility to improve our communication about medical error.

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