Guilty, Afraid, and Alone — Struggling with Medical Error

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Since 1999, health care professionals have been focusing on To Err Is Human, the Institute of Medicine report that sounded alarms about medical error. As we have strived to reduce the rate of errors, systems-based practices such as electronic order entry and procedure checklists have proliferated. Meanwhile, little attention has been paid to the second half of the adage — “to forgive, divine.” How can we characterize and address the human dimensions of medical error so that patients, families, and clinicians may reach some degree of closure and move toward forgiveness?

In interviews that our group conducted for a documentary film, patients and families that had been affected by medical error illuminated a number of themes. Three of these themes have been all but absent from the literature. First, though it is well recognized that clinicians feel guilty after medical mistakes, family members often have similar or even stronger feelings of guilt. Second, patients and their families may fear further harm, including retribution from health care workers, if they express their feelings or even ask about mistakes they perceive. And third, clinicians may turn away from patients who have been harmed, isolating them just when they are most in need.

Despite acknowledging that they probably could not have prevented the error, family members often berate themselves and feel guilty about not keeping close enough watch. A young man with sickle cell anemia and well-documented life-threatening reactions to morphine received this medicine despite his family's repeated warnings. When renal failure and coma resulted, his sister noted, “The feeling was impotence, because you can't stay with a patient 24 hours a day. That's why you rely on hospitals — you rely on nurses. You feel like you failed your family in terms of 'I should have been there.' That's a guilt that everyone shares.”

Guilt persists in the daughter of a woman who died after a series of errors culminating in a missed case of pneumonia. Although the daughter is a nurse, she could not gain entry into her mother’s circle of clinicians, who closed ranks after the errors occurred. “The nurses were ruder to me than you can ever imagine, and the doctors wouldn't tell me anything,” she said. “They looked at me like I was a dumb little girl. I became so addled that I couldn't act decisively and get her out of there to another hospital. I'll never get over my guilt.”

Clinicians who feel guilty after a medical error may have parallel feelings of fear — fear for their reputation, their job, their license, and their own future as well as that of their patient. Although full disclosure of medical errors is increasingly recognized as an ethical imperative, health care providers often shy away from taking personal responsibility for an error and believe they must “choose words carefully” or present a positive “spin.” Hospitals, insurers, and attorneys frequently advise physicians against using trigger words, such as “error,” “harm,” “negligence,” “fault,” or “mistake.” The result can be an impersonal demeanor that leads patients to view physicians as uncaring. To date, approximately 30 U.S. states have adopted “I'm sorry” laws, which to varying degrees render comments that physicians make to patients after an error inadmissible as evidence for proving liability. However, until such statutes become universal and are accepted by health care institutions, frightened clinicians are left to struggle with conflicting personal moral principles, professional ethics, and institutional policies.

The patients and families interviewed for the film also spoke of fear — indeed, fear of retribution or future poor treatment was the reason most frequently cited for declining to be interviewed. Because of the power dynamics between physicians and patients, questioning the expertise or skill of an authority figure is particularly fraught for the least empowered members of society — members of minority groups, immigrants, and non-native English speakers. Several such persons who were approached for interviews feared they would be investigated and possibly punished by “the authorities” if they told their stories. More strikingly, some patients and family members were afraid that confronting medical personnel might lead to further injury. Explained one patient whose subdural hematoma had been missed by clinicians: “I was frightened to complain any more — scared that, you know, you hear about people being mistreated in the hospital. I was scared that I would get more mistreated.”

Given the nature of the emotions provoked by medical error, feelings of isolation can be particularly harmful. Family members of injured patients told us, “What we needed was for someone to
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reach out and connect with us in human terms.” “The sense that somebody could empathize and know what I was feeling . . . that was almost totally lacking.” Clinicians, too, often suffer alone after making mistakes, agonizing over the harm they have caused, the loss of their patients’ trust, the loss of their colleagues’ respect, their diminished self-confidence, and the potential effects of the error on their careers. “Did I do something wrong? You get that sinking feeling probably on a daily basis,” one physician told researchers.²

When providers back away from injured patients and their families, it may be because of their own feelings of guilt, fear, and isolation, compounded by legal or institutional advice. Paralyzed by shame or lacking their own understanding of why the error occurred, physicians may find a bedside conversation too awkward. They may also be unwilling or unable to talk to anyone about the event, inhibiting both their learning and the likelihood of achieving resolution. Such avoidance and silence compound the harm. A physician—patient with third-degree burns from a heating blanket applied to his anesthetized skin said, “The most important point would be to go see the patient more, not less.” His wife added, “I would have still felt great pain, but I wouldn’t have felt as alone.”

How can patients, families, and clinicians move beyond these feelings and approach closure and forgiveness? Honest and direct communication may be the best antidote. “You have no idea how far a ‘sorry’ will go,” said one patient with a systemic infection that occurred after a surgeon perforated his ileum while resecting a colon carcinoma. Families and patients don’t want “spin doctors.” The daughter of a woman who was injured after receiving a medication to which she had a documented allergy commented on her mother’s preserved trust in her physician: “The reason [the physician’s] apology felt genuine was because it was direct. He didn’t beat around the bush. He didn’t try to cover things up.” Rather than simply assigning blame, patients and families want both to understand their situation fully and to know what the event has taught caregivers and their institutions.

Withholding such information can lead to lawsuits if despairing patients feel that a mistake has not been taken seriously. Above all, silence and evasion breed distrust. One father, whose daughter with end-stage leukemia had received an intravenous medication despite her known allergy commented on her physician: “The reason [the physician’s] apology felt genuine was because it was direct. He didn’t beat around the bush. He didn’t try to cover things up.” Rather than simply assigning blame, patients and families want both to understand their situation fully and to know what the event has taught caregivers and their institutions.

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When things go wrong, the experiences of patients and families and those of clinicians may be strikingly similar and yet damagingly divisive. Although apology and disclosure are necessary, they may be insufficient to elicit forgiveness, which encompasses shared understanding, rekindled trust, acceptance, and closure. Everyone involved needs an organized structure that restores communication and supports emotional needs. First steps might include creating structured curricula for professionals addressing both error prevention and response, removing stigma from transparent reporting systems, and deploying a system of expert first responders who guide patients and clinicians when an error occurs.⁵

Perhaps most important, building bridges to injured patients necessitates including them and other patients in the development of solutions. Patients and families will bring ideas to the table that expand the horizons of health care professionals. The yield from working in partnership could be enormous, both improving people’s experience with medical error and preventing harm from occurring in the future.

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