

ON NOTEBOOKS AND TRUST

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We recently asked a group of critical care nurses and physicians how their work had changed over the past few years. We expected (and had steeled ourselves) to hear the litany of negative themes dominating the press of late: nursing shortages, daunting workloads, low reimbursement rates, poor morale, and a turbulent healthcare environment. None of these was mentioned. The number-one change they identified was a growing mistrust among patients and their families of caregivers. They explained that family members of patients hospitalized in the intensive care unit (ICU) took copious notes at the bedside, writing down nurses' and doctors' names and what each one did and said. They described patients who grilled each nurse about the nature and purpose of the medications that were being given and compared one set of answers to another. The nurses and physicians grieved for the time when patients and families trusted critical care professionals—*trusted* their competence, knowledge, and dedication—until proven unworthy of that trust. Today, it appears that our patients and their families *mistrust* until proven otherwise.

What changes in the healthcare system have led to this erosion of confidence on the part of our patients and the public? We can think of four.

Patients Feel Vulnerable

Certainly, the publication of the Institute of Medicine's report¹ on errors in patient care and the accompanying publicity² alerted many consumers to the high number of deaths that occur needlessly in hospitals each year. Investigators have extrapolated from 2 limited studies that medical mistakes kill up to 98 000 Americans annually.³ One study documented an error rate of almost 6% in medication orders for children hospitalized in 2 urban teaching hospitals, with 3 times the rate of potential errors caught before

drug administration compared with a similar study of hospitalized adults. Thus, the most vulnerable patients (children) seemed to be most at risk. What parents would read those results and not plan for around-the-clock surveillance if their child became critically ill? What spouse reading the headline of the *Chicago Tribune*, "Nursing Mistakes Kill, Injure Thousands,"³ would not arrange to stay nearby to protect his or her husband or wife who was admitted to the hospital?

Far fewer deaths are ascribed to terrorism, airplane travel, or defective products (such as a certain manufacturer's tires) than to medical errors, and yet the government has not taken quick action to identify and rectify the problems that led to these deaths. Some people have questioned why the government has been so slow to respond to errors in patient care and have cautioned consumers that they cannot trust the government to protect them in this very important arena.⁴ Thus, consumers once again are urged to be vigilant and to trust no one.

Hospital staffing is the second change that has undoubtedly made the American public feel more vulnerable. An article that appeared a few months ago in *Reader's Digest*, "How Hospitals Are Gambling With Your Life," began with the sentence, "When you press that call button, don't expect a real nurse to come through the door."^{5(p151)} The author provided readers with many examples of unlicensed personnel across the country who were assisting in surgery, giving injections, and monitoring acutely ill patients, all with dire results. The author recommended that patients and family members carefully interrogate caregivers that appear to be nurses to make sure that they are indeed licensed RNs. The author also suggested that hospitals have been less than forthcoming about the increased percentage of unlicensed personnel involved in patient care activities, allowing these individuals to appear to be registered nurses through confusing job titles and unclear identification badges.

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Based on this article and others like it in the lay press, the onus would seem to be on the public to sort out the competent from the incompetent. Nowhere is this “sorting” more important than in the high technology and highly invasive environment of the ICU, where patients are at their most vulnerable.

Frazzled Strangers as Caretakers

A third change has been the move to the hospitalist and intensivist model of care. Although these specialists may be in the best interest of the patient, because the physician making decisions about medical care is highly experienced in the care of acutely ill patients, the patient and family members no longer see a physician who has personal knowledge of the patient. Primary physicians who have large panels of patients (usually over 2000 in a typical health maintenance organization) have little time or incentive to make daily hospital rounds. Within this model of care, patients and family members may never see a familiar face during an entire hospitalization. They may longingly remember the time when their “family doctor” came each day to the hospital and was the connection with their normal past. He or she was the person they could count on to watch over them until discharge and beyond.

This third force places even more responsibility on nurses. Nurses are the “face” of healthcare for hospitalized patients and their families, and it is they who must communicate a sense of caring and competence in an otherwise frightening environment. Unfortunately, nurses may be too tired and frustrated to have much enthusiasm for this role.^{6,7} This change in the way nurses view their work—their sense of frustration and burden—is the fourth change that, in our opinion, contributes to the erosion of trust.

Nurses have done an excellent job of bringing their frustrations about the many recent changes in healthcare to the public’s attention. If we asked any newspaper reporter across the country to identify the number-one story in healthcare today, our guess is that it would be the nursing shortage. All such stories begin with the dire statistics of an aging workforce and decreased enrollments in nursing programs, but then the next part of the story is the dissatisfaction of nurses who are currently in the profession. The shortage has provided a highly visible and effective platform for nurses to catalogue the problems experienced by those who work in hospitals today. The lay public must read newspaper interviews or survey results and wonder if “their” nurse could even muster the energy to get to the bedside to care for them (particularly after a 16-hour day of mandatory overtime).

It is little wonder that patients and their families feel mistrustful and anxious.

Trust

Trust is a precious gift. When adults become severely ill, they revert to a time in their earlier lives when survival depended upon the good will and competence of someone else, usually a parent. Acutely ill patients can no longer take care of themselves and are dependent on the good will, competence, and kindness of someone else. At the bedside of a critically ill patient, nurses and doctors become that “someone else.” Life support means just that. We maintain a patient’s life by providing sustenance, circulatory support, and ventilation.

Many of our acutely ill patients are confined to bed because of the severity of their illness or the level of technology required for monitoring. As each nurse or physician comes to the bedside of a critically ill patient, the patient can ask, “Is this person going to care what happens to me?” “Does this nurse look tired or distracted?” “Does he (she) know what he’s doing?” Conscious patients must be terrified of the dependence they feel and their inability to take care of their own needs. Their only option is to trust.

Helping Patients Feel Safe

According to a recent study,⁸ acutely ill patients are predominately focused on maintaining a feeling of safety. A sense of safety is based on the patient’s view of the ICU staff (ie, their level of competence and knowledge, as well as their concern for patients), the presence of family and friends, and strong religious beliefs. Patients who described themselves as feeling safe also said that they knew what was happening to them and had confidence that they would ultimately recover. Many of the patients interviewed described the ICU as a terrible place where they felt frightened and fearful. Periods of confusion were characterized by a loss of control over the environment and their bodily functions. Patients spent a great deal of energy during their ICU stay trying to interpret what was happening to them. They eavesdropped on daily rounds and on staff conversations (often believing that staff members were talking about them when they were actually talking about someone else). They asked family members to interpret events and serve as liaisons with staff. This last finding may partially explain why the nurses and physicians we spoke with have noticed an increase in family involvement at the bedside, seeing relatives who feel that they must watch and monitor nursing activities to prevent the patient from being harmed.

Reestablishing Trust

In the big picture, hospitals and healthcare systems must address the many deficiencies in hospital organization, work design, and care structures that are the unfortunate result of the reengineering of the past decade. Many of the forces operating to erode patient and family trust (such as unqualified caregivers, unsafe patient-staff ratios, mandatory overtime to compensate for staff shortages, and inadequate resources for care) ultimately must be addressed in changes in the system. The solutions, many of which are well described in the literature^{9,10} and exist in some hospitals today,¹¹ may be legislated by the government if administrators and insurers do not act quickly.

But we cannot wait for the system to change. Patients need to feel safe today—now—on this shift. A number of strategies exist to help patients and their families trust us. We welcome your suggestions and thoughts about these strategies in Letters to the Editors. In the meantime, we offer a few of our thoughts.

- Recognize that patients are frightened and look to you for protection. Reassure them by providing as much information as possible about what is happening in terms of procedures and care.

- Communicate clearly and often with both patients and their family members. Use names (yours and theirs), and make sure that they know your credentials and your role in their care at all times.

- Give families unlimited access to the patient. In those special cases in which access must be limited for a short time, ensure that the family and patient understand the reason. Restricted visiting policies are an excellent way to set up a “we-they” dynamic between staff and families and reflect a paternalistic (or maternalistic) system that is an anachronism.

- Make sure that all of the individuals caring for the patient (nurses on different shifts, physicians, respiratory therapists, etc.) are working from the same plan of care and communicate in a unified voice. Being on the same page requires excellent interdisciplinary and intradisciplinary collaboration—a challenge in every environment, but none more so than today.

- Hold conversations about the patient well outside the hearing of the patient, even when the patient appears to be comatose. Who knows?

- Complain to colleagues about problems in the unit or with hospital resources *in private*. Patients and families can do nothing to help and knowing that you are unhappy or do not have sufficient support can only add to their fear of harm and sense of powerlessness.

- Contribute to and help develop your institution’s Web site. Patients’ discomfort often arises from their intense fervor to find information on the Internet and then their inability to deal with the inconsistencies they download.

It is easy to be generous of spirit in the good times. Unfortunately, these are not the good times. It would quite wonderful, though, if we could help families put away those notebooks.

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