ANNALS OF MEDICINE

BEING THERE

Should patients' families see what happens in the emergency room?

BY JEROME GROOPMAN

One afternoon in 1982, a twenty-eight-year-old Michigan state trooper named Craig Scott stopped a speeding car on U.S. Route 127, outside Jackson. Scott discovered that the car, a Camaro, had been stolen, and arrested the driver. As Scott was helping the driver into the back of his patrol car, a passenger in the Camaro pulled out a .38-calibre revolver and shot the trooper three times in the back. Bleeding profusely and gasping for breath, he was taken by ambulance to Foote Hospital, in Jackson. As doctors tended to Scott in a trauma room, his wife arrived at the hospital, and so did several of his colleagues. In the lobby of the emergency room, Scott's wife pleaded with the hospital's chaplain, Reverend Hank Post, to let her see her husband, and Post agreed to convey her request to the physician in charge of the trooper's care.

"We debated back and forth," Post recalled. "The staff was very uncomfortable." Finally, the doctor went to Scott's wife and explained that the hospital prohibited family members from attending resuscitations. But she continued to insist, and eventually the doctor gave in. "It was hard to deny her with all those blue shirts staring you down," said Post, who accompanied the woman to her husband's bedside.

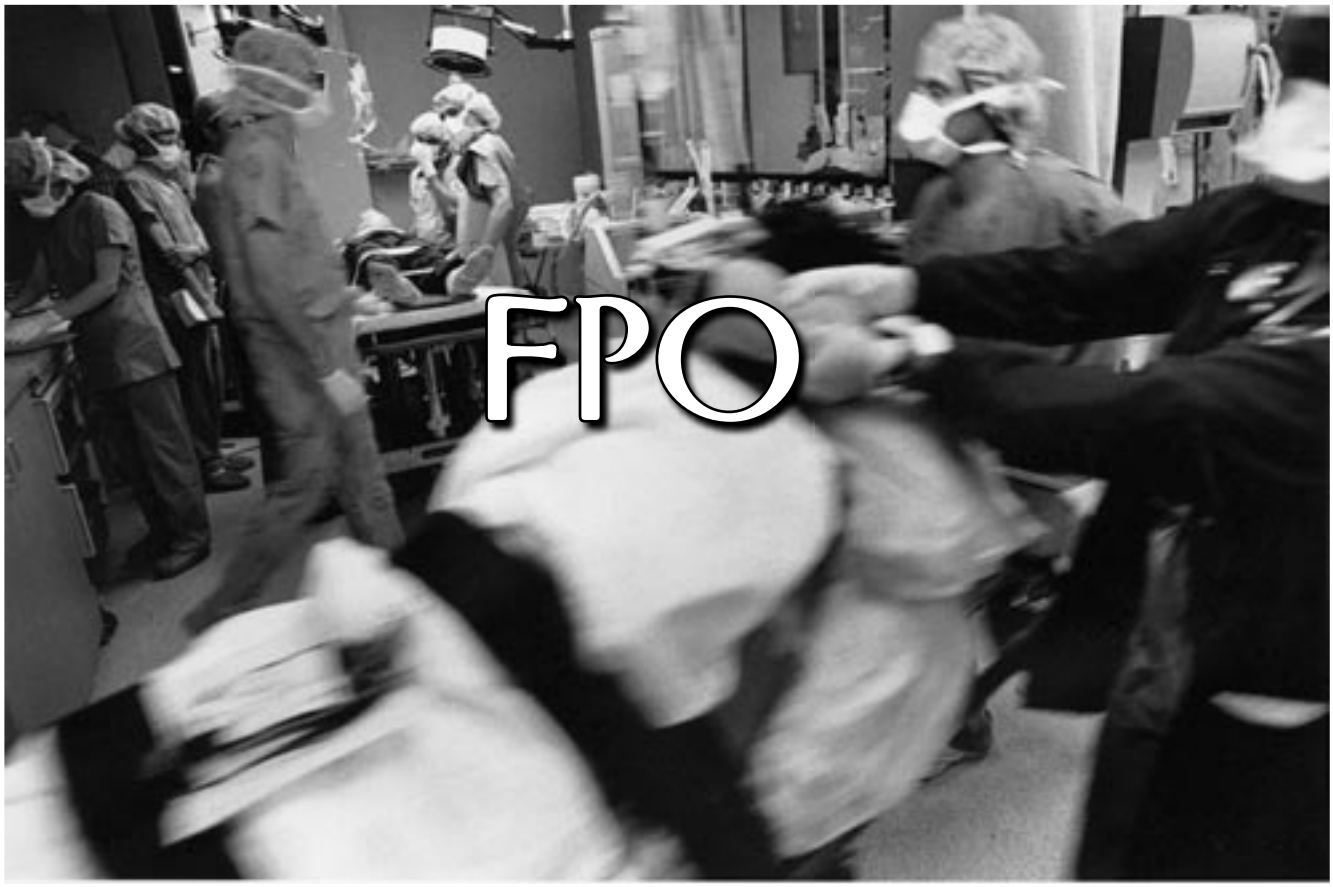
They watched as Scott was given blood transfusions and sent to the operating room for surgery, where he died. Over the next week, Post talked to doctors and nurses at the hospital about allowing patients' family members to accompany them inside the E.R. The doctors and nurses dismissed the idea; many argued that laypeople would have trouble coping with the stress of witnessing resuscitation efforts and patients' deaths. Post disagreed. Ordained in the Christian Reformed Church, a Protestant denomination, he was inspired by the Calvinist tradition of challenging prevailing dogma. He told me that he regarded his effort to open Foote Hospital's emergency room to families as a campaign for "human rights."

For several years, whenever Post was on call, he urged physicians to let patients' relatives sit in on resuscitation attempts, and, when doctors agreed, he stood with the family members next to the patient's bed. "It moved grieving along," Post said. "The families saw quickly how hopeless things were, and, by being present, the family can own part of what went on." In 1985, Post sent surveys to seventy people who had witnessed resuscitation attempts in Foote Hospital's E.R. Among the questions he asked was "Would you choose to participate again if the opportunity were presented to you?" Forty-four of the forty-seven respondents said yes. Several added that although the experience had been unpleasant, it had helped them come to terms with a relative's death.

In 2003, emergency rooms in the United States treated nearly a hundred and fourteen million people; about one in every hundred received CPR or underwent another kind of resuscitation procedure. Resuscitations are gruesome—physicians occasionally have to split ribs or cut into a windpipe in an effort to keep someone who is bleeding or unconscious alive—and just fifteen per cent, at most, are successful. Foote was one of the first American hospitals to permit patients' relatives to witness these procedures, but the practice, which is known as "family presence," is spreading, promoted in many instances by chaplains and nurses over the objections of doctors. (There are no reliable data, but advocates estimate that as many as half of American hospitals allow some form of family presence.)

In 1993, at the annual meeting of the Emergency Nurses Association, Patricia Howard, an emergency nurse from

Kentucky, submitted a resolution to the group's general assembly endorsing the policy on the ground that "when family members are prohibited from visiting before . . . death, the grief process may be hampered and left unresolved." To her surprise—the association had never discussed family presence—the resolution passed by a large majority. "We've always taken excellent clinical care, but not always excellent psychosocial care," Howard, who just finished a term as the association's president, told me. Family members who witness a resuscitation can help decide when to end efforts to revive the patient, she said. "We have had incidents where families say, 'O.K., you've done enough.' " Like many proponents of family presence, she argues that today Americans are better prepared for the gore of resuscitations than they were ten years ago, because they've seen realistic imitations of such procedures on television. "'ER' and a lot of graphic programs have made the difference in terms of public expectations and knowledge," she said.



The public is well informed about what goes on in the E.R., but not about likely rates of success. Photograph by Eugene Richards.

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"ER" débuted on NBC on September 19, 1994; two years later, more than thirty million Americans were watching the program each week. Unlike previous medical dramas, such as "Dr. Kildare" and "Ben Casey," from the nineteen-sixties, which featured doctors in pristine white lab coats calmly talking at patients' bedsides, "ER" and its competitors, "Chicago Hope" and "Rescue 911," purported to depict emergency medicine as it is actually practiced. "ER," which was set in a fictitious Chicago teaching hospital, incorporated abundant medical jargon and relied on Steadicams—cameras mounted on the body—and multiple plotlines to create an aura of authenticity. (A typical episode featured patients suffering from severe asthma, premature labor, injuries sustained in a car accident, drug addiction, a genital rash, and heart failure.) In 2005, the American College of Emergency Physicians presented the series with an award for "educating the public about critical issues."

In 1996, researchers at Duke University Medical Center and at the University of Chicago analyzed ninety-seven episodes of "ER," "Chicago Hope," and "Rescue 911" and found that of the sixty patients who underwent resuscitations on the shows nearly two-thirds on "ER" and "Chicago Hope," and all on "Rescue 911," survived. Only one patient on the programs, a sixteen-year-old boy on "Rescue 911" who had inhaled toxic chemicals, endured lasting complications; in fact, patients who survive resuscitations often have brain damage or debilitating neurological conditions. The researchers, who published their findings in an article in *The New England Journal of Medicine*, maintained that "Rescue 911," in particular, tended to feature "miracle cases": younger people surviving acute injuries, rather than elderly patients with chronic heart and lung disease, who account for the majority of resuscitation patients. "The survival rates in our study are significantly higher than the most optimistic survival rates in the medical literature, and the portrayal of CPR on television may lead the viewing public to have an unrealistic impression of CPR and its chances

for success," the researchers wrote.

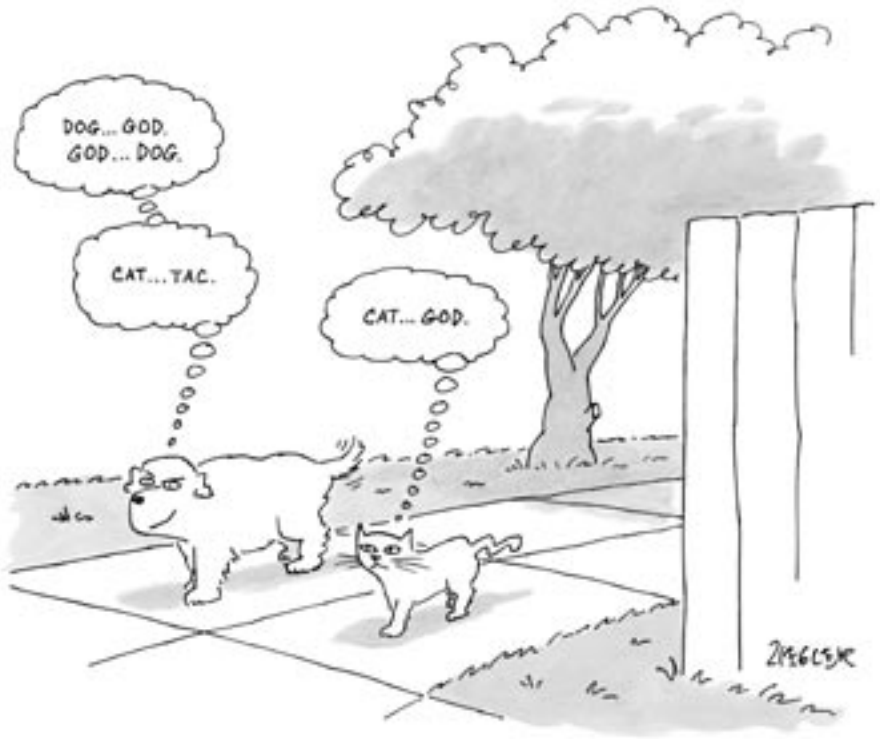
A few years later, two doctors and a professor at the Brody School of Medicine at East Carolina University, in Greenville, North Carolina, sent four hundred surveys to local churches asking members about their views on resuscitation. Nearly half of the two hundred and sixty-nine respondents cited television as a primary source of their information, and predicted, on average, that the survival rate from CPR was seventy per cent. In an analysis published in *Academic Emergency Medicine*, in 2000, the survey's authors cited the 1996 television study, writing that their own research "confirms that the events on these types of shows may be shaping and fueling the public's misconceptions of the effectiveness of CPR."

At the same time, patients and their families have become increasingly involved—and influential—in all aspects of medical care. In the mid-eighties, as the first anti-viral drugs for treating AIDS were being developed, activists demanded to participate in the design of clinical trials directed by the National Institutes of Health and pharmaceutical companies. Inspired by the activists' example, breast-cancer patient-advocacy groups made similar requests. The AIDS groups interrupted meetings and staged "die-ins" at the N.I.H., and, eventually, the physicians in charge of planning the clinical trials agreed to their demands. Laypeople now routinely sit on committees at the N.I.H. and on hospitals' institutional review boards, which assess the ethicality and scientific merit of clinical trials, particularly those involving experimental drugs or procedures. Yet family presence in emergency rooms, which is part of this larger trend, remains controversial. Not only does it represent an incursion by the public into medicine's inner sanctum; more than any other recent development, it reveals the extent to which the power to decide how medicine is practiced is no longer an exclusive prerogative of doctors.

The first emergency rooms were created about a hundred years ago, when hospitals began designating specially equipped "accident rooms" for the treatment of patients with severe injuries and illnesses, as well as for those who couldn't afford a family doctor. According to Brian Zink, an associate professor of emergency medicine at the University of Michigan and the author of "Anyone, Anything, Anytime: A History of Emergency Medicine" (2005), surgeons were largely responsible for the design of modern emergency rooms, which typically resembled O.R.s, with bright overhead lights and beds separated by movable partitions. Partly in order to maintain a sterile environment in the rooms, access was strictly controlled. "De facto, family members were excluded," Zink said.

After the Second World War, thousands of families moved from rural areas to cities, where there were not enough general practitioners to treat them, and by the middle of the century hospitals had taken over from family doctors the responsibility of caring not only for the seriously ill and injured but also for the dying. (Until the nineteen-sixties, many ambulances were simply repainted hearses, which were owned and operated by funeral homes.) As Gabe Kelen, the chairman of the Department of Emergency Medicine at Johns Hopkins University, put it, "Death became sanitized, and in the hospital families were spared from seeing the agony of dying." This is precisely what advocates of family presence want to change. (Policies regarding sick or dying children have traditionally been more flexible; many hospitals allow parents to remain with a child during at least some emergency medical procedures.)

Four years ago, Massachusetts General Hospital became one of the first hospitals in Boston to adopt guidelines on family presence. One afternoon recently, Ann Marie, a forty-seven-year-old woman, rode to M.G.H. in an ambulance with her father-in-law, Daniel, who had collapsed in a parking lot behind his apartment building in East Boston. (Names have been changed to protect the family's privacy.) Daniel was seventy-one and had recently spent a month at the hospital, where he had been treated for congestive heart failure. When he collapsed, he had been walking home from a local racetrack, where he had placed some bets. A letter carrier saw him fall and called 911. A team of firemen arrived and administered electric shocks to Daniel's chest in an effort to jump-start his heart. Then medics arrived in an ambulance and continued to try to revive him. A resident of Daniel's building saw the ambulance and called Daniel's ex-wife, who called Ann Marie. By the time Ann Marie got to the parking lot, the medics were preparing to lift Daniel into the ambulance on a stretcher. On the way to M.G.H., the medics gave Daniel oxygen



through a tube inserted into his throat.

Patricia Mian, a psychiatric clinical nurse specialist, met the ambulance at the hospital. As the medics wheeled Daniel to a bed in the trauma area, Mian recalled, she told Ann Marie, "If you would like to be with him, you can. I will be with you as well, explaining everything that happens." Ann Marie said that she wanted to stay with Daniel, so Mian escorted her to the head of his bed.

Ann Marie remembered watching as one of the medics told the resuscitation team about Daniel's condition. A nurse named Eric Driscoll took notes on a clipboard, while another nurse cut away Daniel's clothes with a pair of shears. Keith Marill, an attending emergency-department physician, stood at Daniel's right hip; Kriti Bhatia, the senior resident in charge of the resuscitation, stood at the foot of the bed. A medical intern and a surgical resident were also present.

Daniel's skin was blue from the chest up, indicating that his circulation was impaired, and his pupils were dilated.

"We need central access," Bhatia remembered instructing the surgeon. "Please put in a femoral line." The surgeon splashed an iodine solution over Daniel's groin and pressed a gloved finger into the cleft between his lower abdomen and his left thigh, searching for a pulse in the femoral artery.

"He's pulseless," Marill recalled saying, palpating the same area on Daniel's right side. "Try your best to hit the vein."

The surgeon stuck a large-bore needle into Daniel's groin several times before he found the femoral vein. Then he threaded a long catheter through the vein into the inferior vena cava, a large vessel that rises from the abdomen to the heart. A nurse attached a bag of saline solution to the catheter.

As the intern compressed Daniel's chest, the nurse forced oxygen into his lungs by squeezing a balloon-shaped bag that was attached to the tube in his trachea. Gradually, Daniel's blue skin turned ivory. Ann Marie placed her hands on his head to comfort him. She noticed that his eyes were wide open and unblinking, which upset her. She glanced at Bhatia but, fearful of distracting her, didn't say anything.

Mian encouraged Ann Marie to talk to Daniel. "It's O.K., Dad," Ann Marie told him. "It's O.K. I'm here."

"He's in P.E.A.," Bhatia said, looking at a monitor by the bed. "Give him epinephrine and atropine." P.E.A. stands for pulseless electrical activity; Daniel's heart muscle was unable to pump enough blood to generate a pulse.

Ann Marie saw a nurse inject the medicines, but she didn't catch the names of the drugs or understand what they were for: to help Daniel's heart contract effectively and move blood faster through his vessels. Instead, she focussed on Daniel's face. Each time the intern pressed on Daniel's chest, it seemed to her that his bulging eyes might jump out of his head.

"His potassium may be high," Bhatia said. "I want a bolus of D50, ten units of insulin, with calcium and bicarb." (D50 is a highly concentrated glucose solution that, in the presence of insulin, will help draw excess potassium from the blood into the cells; calcium helps the heart contract.)

"He has a pulse!" Marill announced. The intern stopped pumping on Daniel's chest.

"His EKG shows a heart rate of eighty-four," Bhatia told the team. Driscoll noted that the resuscitation attempt had been under way for five minutes when Daniel achieved a stable blood pressure of a hundred and twenty-five over seventy-two.

Ann Marie had no idea that Daniel had revived. "I didn't know that his heartbeat had ever returned," she told me later.

Daniel sustained the blood pressure for seven minutes. Then Bhatia said, "Oh God, he lost his pulse."

"He's got a wide complex with an accelerated ventricular escape rhythm," Marill said, looking at the monitor. Once again, Daniel's heart had ceased to beat effectively.

A nurse administered more epinephrine and atropine, and Driscoll made notes on his clipboard.

"He hasn't got his pulse back," Marill said.

The intern began to sweat as he pressed on Daniel's chest.

"Keep pumping," Bhatia said. "We need an ultrasound." She lowered a wand over Daniel's chest which bounced sound waves off his heart. One cause of pulseless electrical activity is cardiac tamponade, a condition in which fluid accumulates around the heart and compresses it like a vise, preventing blood from entering the organ. The ultrasound would detect tamponade and show the strength of any muscular contractions.

"Does he have any cardiac activity?" Bhatia asked.

"Nothing happening," Marill said as he examined the ultrasound image. Daniel's heart muscle was flaccid.

"Does anyone have any other thoughts, suggestions, or is there anything else we should do?" Bhatia asked.

The doctors and nurses looked at her in silence.

"O.K., I guess this is it, then," Bhatia said. Marill placed his stethoscope over Daniel's chest and listened for breath sounds. There were none. He felt Daniel's neck for a pulse and shook his head. Finally, he shined a penlight in Daniel's eyes. The pupils didn't respond.

Driscoll noted that Daniel was declared dead at 2:35 P.M., seventeen minutes after he arrived at the E.R.

Later, Ann Marie said that she thought that Daniel had been dead for a long time before the doctors and nurses stopped their efforts. She was troubled by his fixed stare, which made her feel that Daniel wasn't at peace, and, at her request, Mian asked a nurse to close his lids.

Ann Marie told me that Daniel "was the third family member to die in my arms." In 1974, she had been at her father's bedside at M.G.H. when he died, from complications of advanced diabetes, and she had cared for her mother until her death, ten months later, from brain cancer. Ann Marie said that she wasn't sure why she had decided to witness her father-in-law's resuscitation. "I think he was probably already dead in the parking lot," she said. "But it's so sad to die alone. I wouldn't want to die alone. I didn't want him to die alone. And when I was in the room I knew the doctors and nurses did everything they could."

I asked Ann Marie how she felt about what she had seen in the emergency room. "I used to be very sen-

sitive," she said. "My mother's and father's deaths made me stronger." Nevertheless, she added that she often pictured Daniel's eyes "jumping" in synch with the intern's chest compressions. "The whole thing was traumatic for me," Ann Marie said. "But I try to bypass it by making myself think of good things."

Few attempts have been made to measure the psychological impact of family presence, either on patients' families or on doctors and nurses in the E.R. Most of the existing studies consist of surveys and involve so few people that they cannot be considered significant. Addenbrooke's Hospital, in Cambridge, England, instituted a policy of family presence after completing a single study, in 1998, involving twenty-five relatives of people who had undergone a resuscitation at the hospital. Thirteen relatives were invited to witness the procedure (eleven chose to do so); twelve, who formed the control group, were not. Researchers surveyed eight relatives who had watched a family member die, at three months after the procedure and again three months later, and found no evidence of trauma. Moreover, these relatives said that they were pleased with their decision to observe the resuscitation. Despite the study's small size, it has been cited repeatedly in medical and nursing journals as proof of the therapeutic value of family presence.

In August, 2000, the journal *Circulation* published new guidelines for emergency cardiovascular care from the American Heart Association, which recommended that family members be allowed to witness resuscitation attempts. Two months later, at the annual meeting of the American College of Chest Physicians, in San Francisco, researchers from Tripler Army Medical Center, in Honolulu, distributed a survey about family presence to the attendees, who included physicians, nurses, and health-care workers such as respiratory therapists. Of five hundred and fifty-four respondents, the majority (seventy-eight per cent) opposed family-witnessed CPR for adults. More physicians (eighty per cent) than nurses (fifty-seven per cent) disapproved of the practice. The researchers, who published an analysis of the survey in *Chest*, a leading journal of thoracic medicine, found that where the respondents lived was a better predictor of their attitude toward family presence than the size or type of hospital in which they worked. Health-care workers in the Midwest were most likely to favor the practice (thirty-seven per cent); those in the Northeast least likely (twelve per cent). "While the reasons for these differences are unproven, we speculate that ten years of efforts by the Foote Hospital (Jackson, MI) staff may have taken root in the Midwest, making FWR"—family-witnessed resuscitation—"more acceptable in that region," the researchers wrote.

One group whose members have actively opposed family presence is the American Association for the Surgery of Trauma. In 1999, a team of medical researchers led by R. Stephen Smith, a trauma surgeon and a professor at the University of Kansas School of Medicine, in Wichita, surveyed three hundred and sixty-eight trauma surgeons and twelve hundred and sixty-one emergency nurses to learn their views of the practice. The respondents were asked to agree or disagree with statements such as "I would want to be present during TR"—trauma resuscitation—"following injury of a member of my family." Almost all of the nurses said they agreed with the statement; almost all of the trauma surgeons said they did not. Sixty per cent of the nurses approved of family presence during cardiopulmonary resuscitation and ninety-seven per cent of the surgeons disapproved, saying that it interfered with patient care and increased stress on the doctor.

In a 1999 report for the A.A.S.T. summarizing the results of the survey, Smith and four co-authors cited Federal Aviation Administration regulations instituted in 1981 to reduce the number of airplane accidents caused by distracted pilots. Known informally as the "sterile cockpit rules," the regulations prohibit crew members from engaging in activity that is not "required for the safe operation of the aircraft"—and which the F.A.A. defined as unnecessary conversation, eating, reading, radio communications, and public-address announcements. Smith and his co-authors argued that resuscitations involve tasks as demanding as those required to fly a plane. Like pilots, they wrote, emergency-room teams must assimilate large quantities of data in a short time and make quick decisions; potential distractions, such as the presence of a family member, could jeopardize the success of a resuscitation.

Smith argues that the debate over family presence has exposed a conflict in medicine between, on one side, chaplains and nurses, who worry about fam-

TROY

We had a drink and got in bed.
That's when the boat in my mouth set sail,
my fingers drifting in the shallows of your buzz cut.
And in the sound of your eye
a skiff coasted—boarding *it*
I found all the bric-a-brac of your attic gloom,
the knives from that other island trip,
the poison suckle root lifted from God knows where.
O, all your ill-begotten loot—and yes, somewhere,
the words you never actually spoke,
the woven rope tethering
me to this rotting joint. Touch me,
and the boat and the city burn like whiskey
going down the throat. Or so it goes,
our love-wheedling myth, excessively baroque.

—Meghan O'Rourke

ilies' emotional needs, and, on the other, physicians, who are primarily concerned about the quality of clinical care. In this sense, the debate is a sign of how power has shifted within the hospital; a movement led by chaplains and nurses to change a long-standing medical protocol would have been inconceivable when I was a resident in the emergency room thirty years ago. (Chaplains' tasks were limited to assisting patients with prayer and delivering last rites, and nurses, particularly in surgery, were viewed as handmaidens who should take orders but never give them.)

Smith's hospital has addressed the conflict by devising a compromise: patients' families are allowed to join them in the E.R., but only after invasive procedures have been completed and at the discretion of the trauma surgeon. Even so, Smith said, a family member's presence has sometimes been disruptive. In one case, a woman suffering from multiple fractures and internal injuries was brought to the hospital by her husband, who wanted to join her in the E.R. Smith and the other physicians who were treating the woman suspected that she might be a victim of domestic abuse and worried that she would be reluctant to recount her medical history in front of her husband. Eventually, the man was persuaded to remain in a waiting room. (The doctors determined that the woman had indeed been abused.)

Smith believes that hospitals should retain the right to invite a patient's relatives into the E.R. on a case-by-case basis. At the same time, he said, laypeople need to realize that they may not understand much of what they see there. "Even medical students don't know why certain things are done during trauma resuscitation," he said. "It's like me taking a tour of a nuclear power plant."

The hospital where I practice, Beth Israel Deaconess Medical Center, in Boston, does not encourage patients' family members to witness resuscitations, though there is no official policy. Lachlan Forrow, an internist who directs the hospital's ethics programs, said that some doctors have favored family presence on the theory that if a patient's relatives saw how violent resuscitations can be they would be more inclined to agree to end efforts to keep the patient alive. But, he said, there is no solid evidence to support this view. A more fundamental problem, Forrow argues, is that laypeople don't necessarily trust doctors to make the right decision. "If the symptom of lack of trust is addressed by having blood splattering on the walls, then as physicians we've gotten ourselves into some kind of weird dynamic," he said. Forrow points out that there is no proof that witnessing a failed resuscitation is more therapeutic for a grieving family member than being told about it afterward by a physician. "Seeing a health-care provider inflict physical pain or disfigure the body of a loved one?" he said. "It seems to me that we should be able to accomplish transparency without that degree of brutality."

Keeping families out of the emergency room, however, ultimately may be impossible. "We are entering an era of openness in every field," Alasdair Conn, the chief of emergency services at M.G.H., told me. "You want to know whether your stockbroker is a good broker. You want to get a second opinion on a legal decision. It's happening in medicine, too. In many medical situations, there is no one right way to do things. There is this questioning, a search for alternative answers. It's different now, coming out in the waiting room and saying, 'We did everything possible, and your father died.' Then the families ask, 'Did you give the drugs? Did you do this? Did you do that?'"

Conn said that he had opposed family presence at M.G.H. until he imagined himself as a patient's distraught relative. "If my daughter or my wife or any of my relatives were in pain and in the emergency department, I would want to be there with them," he told me. "Even when they start putting in lines, or taking blood, or putting in a chest tube, or doing a resuscitation.

"Let me distill it," Conn continued. "Suppose you had the opportunity to spend the last three minutes on earth with your wife. She was just brought into the emergency room. She is semiconscious, and she is probably going to die. Would you want to say a few words to her, or would you rather be someplace else? I think most people would say that they want to be with her."♦