CARDIOPULMONARY RESUSCITATION ON TELEVISION

Miracles and Misinformation

SUSAN J. DIEM, M.D., M.P.H., JOHN D. LANTOS, M.D., AND JAMES A. TULSKY, M.D.

SPECIAL ARTICLE

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Abstract *Background.* Responsible, shared decision making on the part of physicians and patients about the potential use of cardiopulmonary resuscitation (CPR) requires patients who are educated about the procedure's risks and benefits. Television is an important source of information about CPR for patients. We analyzed how three popular television programs depict CPR.

Methods. We watched all the episodes of the television programs *ER* and *Chicago Hope* during the 1994–1995 viewing season and 50 consecutive episodes of *Rescue 911* broadcast over a three-month period in 1995. We identified all occurrences of CPR in each episode and recorded the causes of cardiac arrest, the identifiable demographic characteristics of the patients, the underlying illnesses, and the outcomes.

Results. There were 60 occurrences of CPR in the 97 television episodes — 31 on *ER,* 11 on *Chicago Hope,* and 18 on *Rescue 911.* In the majority of cases, cardiac arrest was caused by trauma; only 28 percent were due to primary cardiac causes. Sixty-five percent of the cardiac arrests occurred in children, teenagers, or young adults. Seventy-five percent of the patients survived the immediate arrest, and 67 percent appeared to have survived to hospital discharge.

Conclusions. 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. Physicians discussing the use of CPR with patients and families should be aware of the images of CPR depicted on television and the misperceptions these images may foster. (N Engl J Med 1996;334:1578-82.)

IN critical care units and hospital wards across the country, patients and physicians struggle with decisions about whether or not to undertake cardiopulmonary resuscitation (CPR) and other potentially life-sustaining treatment. Often, these decisions are not made on a sound basis. Doctors are frequently unaware of their patients' wishes concerning treatment.[1] Even when physicians are aware, they may find the patients' requests problematic. Ideally, decisions about the prospective use of CPR should be made jointly by the patients and physicians,[2] but for patients to participate in medical decisions, they must be informed about the risks and benefits of a procedure and must incorporate this knowledge into the choices they make.

Patients learn about CPR from many sources, including physicians, family and friends, personal experience, and CPR courses. In a number of studies, however, patients report that they obtain much of their information from the media. For example, Schonwetter et al. found that 92 percent of patients over 62 years of age reported obtaining information about CPR from television, 82 percent from newspapers, and 72 percent from books.[3] In another study, 70 percent of the patients over 74 years of age reported obtaining information about CPR from television.[4] Furthermore, patients often overestimate their likelihood of survival after CPR,[3,5] and this misinformation may lead them to choose to undergo resuscitation in situations in which survival is extremely unlikely.[3,5]

Since television is an important source of information about CPR for patients, we analyzed how three popular medical programs depict CPR. We wanted to see how patients undergoing CPR on television compared with such patients in the real world, and to compare the survival rates after CPR on television with the survival rates reported in the medical literature.

METHODS

Study Design

We viewed all the episodes of the television programs *ER* and *Chicago Hope* during the 1994–1995 viewing season and 50 consecutive episodes of *Rescue 911* broadcast over a three-month period in 1995. The first two programs are fictional dramas set in hospitals; *Rescue 911* shows dramatic reenactments of actual rescues by emergency services throughout the country.

We identified all the occurrences of CPR in each episode. CPR was defined as any situation in which chest compressions were performed on a patient, a patient was said to be having "an arrest," or an unconscious patient was defibrillated for ventricular fibrillation or ventricular tachycardia. We included only instances of arrhythmia identified verbally by one of the characters or clearly observed on a cardiac monitor.

For each occurrence of CPR, we recorded the following information: the patient's sex and age, the patient's location at the time of cardiac arrest (in or out of a hospital), whether the arrest was witnessed, whether CPR was performed by a bystander, the immediate cause of the arrest, and any known underlying illnesses of the patient. We noted the use of chest compressions, rescue breathing, defibrillation, and open cardiac massage during the resuscitation. We recorded whether the patient survived the arrest, whether he or she survived to discharge from the hospital, and the long-term outcome. In addition, if physicians on the programs offered estimates of a patient's chance of survival after CPR, we noted those estimates.

We also documented all deaths that occurred on the programs, re-

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gardless of whether the patient received CPR, and we noted the patient's age and sex, the patient's location at the time of death, and the cause of death. We recorded whether CPR was attempted and whether the death was seen in the program or only referred to by other characters.

To validate our coding methods, two investigators, both board-certified internists, reviewed the first 10 episodes in our series (4 of *Rescue 911,* 3 of *ER,* and 3 of *Chicago Hope*). Each observer was blinded to the other's findings. Since the observers agreed perfectly on their identification of occurrences of CPR, their identification of survivors of CPR, and their estimates of the patients' ages, only one observer rated all subsequent episodes.

Statistical Analysis

Short-term success of CPR is usually defined as the return of the patient's blood pressure and pulse for one hour. Long-term success denotes survival until discharge from the hospital. Rates of short-term survival vary depending on the patient's age, the cause of arrest, coexisting illnesses, the cardiac rhythm at the time of the arrest, and the geographic location. A short-term success rate of 40 percent is the upper limit reported in the literature.[6-19] Reported rates of long-term survival vary from 2 percent to 30 percent for cardiac arrests taking place outside a hospital and from 6.5 percent to 15 percent for arrests inside a hospital.[6-19]

We compared the rates of long-term and short-term success for the occurrences of CPR seen in the television programs with the respective rates derived from all relevant studies in the medical literature. To calculate the sample size necessary for the study to have an 80 percent power of detecting a 20 percent difference between the survival rates seen on television and those in the literature (with an alpha level of 0.05 in a two-sided t-test), we used the highest reported long-term survival rate in the literature, 30 percent. Under these assumptions we needed a sample of at least 43 observed instances of cardiac arrest.

Rates of survival were calculated for each television series separately and for all three combined. The survival rates for all episodes combined were compared with the estimates from the literature of 40 percent for short-term survival and 30 percent for long-term survival, using the z statistic for the normal approximation to the binomial distribution.

Results

The Epidemiology of Cardiac Arrest

We viewed a total of 97 episodes (25 of *ER,* 22 of *Chicago Hope,* and 50 of *Rescue 911*) and observed 60 occurrences of CPR. The majority of cardiac arrests were caused by trauma, such as gunshot wounds, motor vehicle accidents, and near-drowning (Table 1). Only 28 percent were due to cardiac causes, such as myocardial infarction or a primary arrhythmia. Many were due to unusual causes, such as lightning, hypothermia, eclampsia, and pericarditis due to lupus erythematosus. Sixty-five percent of the cardiac arrests occurred in children, teenagers, or young adults (Table 2). Male patients accounted for 44 (73 percent) of the cases; 36 cases (60 percent) occurred outside the hospital. Only seven patients were depicted as having underlying illnesses; these included heart disease, dementia, brain damage, lupus erythematosus, and diabetes.

Survival after CPR

Of the 60 patients who underwent CPR, 46 (77 percent) survived the immediate cardiac arrest (Table 3). The rate of short-term survival was highest on *Rescue 911* (100 percent, a rate that is not surprising in a series that, by intention, presents successful rescues). *ER* portrayed a rate of short-term survival of 65 percent, and *Chicago Hope* a rate of 64 percent.

Table 1. Causes of Cardiac Arrests in Three Television Series.

Cause	No. of Cases
Near-drowning	9
Motor vehicle accident	5
Gunshot wound	8
Stab wound	1
Other trauma	7
Arrhythmia	7
Myocardial infarction	6
Other cardiac cause	3
Sepsis	2
Lightning	2
Electric shock	1
Hypothermia	1
Inhalation of cleaning agent and butane	1
Ruptured abdominal aortic aneurysm	1
Congenital heart disease	1
Diabetic ketoacidosis	1
Pericarditis due to lupus erythematosus	1
Eclampsia	1
Drug overdose	1
Cocaine toxicity	1

Of the 60 patients, 22 (37 percent) clearly survived until discharge from the hospital. Of the 46 patients who were successfully resuscitated by CPR, 6 died soon thereafter. For the remaining 18 — all on *ER* — no information was provided about survival until discharge. This series focuses on patients in the emergency department and generally does not provide further follow-up on outcomes. In most cases, however, long-term survival was implied by the fact that the patients survived the arrest in response to which CPR was given and the *ER* staff members considered their work successful.

Survival rates for CPR on these television programs were significantly higher than the highest rates reported in the literature. For short-term survival, the rate of success on television was 75 percent, as compared with 40 percent in the literature ($P<0.001$), and for long-term survival (assuming that the patients on *ER* about whom no explicit information was given survived to discharge), the rate of success was 67 percent (40 patients survived) as compared with 30 percent ($P<0.001$).

Only one survivor of CPR on television, a 16-year-old boy who had inhaled a cleaning agent and butane, incurred any obvious disability. He recovered from his cardiac arrest, completed high school, and became a motivational speaker warning about the dangers of drug abuse. He was shown walking normally with his family, but spoke with a moderate dysarthria in his public appearances. In the real world, disability after cardiac arrest is much more common.[20]

The Portrayal of Death

On the 97 television episodes, 37 patients died. There were 24 deaths on *ER,* 12 on *Chicago Hope,* and 1 on *Res-*

cue 911. The last was a young man in a motor vehicle accident whose family gave permission for organ donation. Of the deaths, 2 were of children, 6 of teenagers, 13 of young adults, 10 of middle-aged adults, and 6 of elderly persons. Twenty-seven of the deaths were of men or boys (73 percent), and 10 were of women or girls (27 percent). Fourteen deaths were due to trauma, seven to heart disease, three to cancer, two to the acquired immunodeficiency syndrome, and four to unknown causes; the remainder were due to miscellaneous causes such as eclampsia, sepsis, drug overdose, aortic dissection, and suicide.

CPR was shown for 18 of the 37 patients who eventually died. In only eight of the situations in which patients died was there a portrayal of discussions about CPR or any reference to do-not-resuscitate orders.

Table 3. Survival after CPR in Three Television Series.

Series	No. of Episodes	No. of Occurrences of CPR	Short-Term Survival after CPR	Survival to Discharge after CPR	Short-Term Survival, Death in Hospital	Short-Term Survival without Follow-up
			number of patients (percent)			
Chicago Hope	22	11	7 (64)	4 (36)	3 (27)	0
ER	25	31	21 (68)	NA*	3 (10)	18 (58)
Rescue 911	50	18	18 (100)	18 (100)	0	0
Total	97	60	46 (77)	22 (37)	6 (10)	18 (30)

*Not applicable. *ER* deals only with events in the emergency department.

The Focus on Miracles

On *Rescue 911,* the term "miracle" was used to describe the patient's survival in 10 of 18 instances (56 percent). The use of the term was supported by the comments of physicians who were involved in the care of the actual patient. In the 10 episodes, the real physicians described their initial extreme pessimism about their patients' chances for a meaningful recovery. After all the patients went on to lead normal lives, family members and health care providers called the recoveries miraculous.

In one episode, a young man was struck by lightning outside his home and initially received CPR from his wife. The paramedic who cared for the patient at the scene said, "It didn't look good. . . . He was in a rhythm called asystole, otherwise known as flatline. We felt the patient would probably not survive." After 30 minutes of asystole, with vigorous advanced cardiac life support, the patient regained a normal sinus rhythm. He was transported to a local emergency department. There, the emergency physician remembered, "His EEG suggested that he was not likely to make any useful recovery." After the patient was placed on ventilatory support, his wife said, "I would go in and hold him, touch him. I was always talking to him. I never gave up hope. . . . They were talking about, if he lived, he had a 1 percent chance of being a functional human being."

Five weeks later, the patient was released from the hospital and went on to a complete recovery. Reflecting on the case, his physician said, "The most amazing thing to me about J.'s recovery is that we were wrong. We had given up hope. His wife did not. She saw us through the extra week, and that made a difference. I think there's no question that if she had lost hope, there might have been a different outcome." The patient's wife herself was even more emphatic. She said, "It truly is a miracle that he is alive."

In the episode about the 16-year-old boy who had cardiac arrest after inhaling a cleaning agent and butane, computed tomography after resuscitation revealed cerebral edema. The boy's physician remembered that "my hopes were going down by the minute." The physician asked the family to consider organ donation if the boy were to die. The patient's mother remembered that "the doctor gave us no hope at all. . . . They were saying that if he came out of it at all, he might be a vegetable." After 17 days in a coma, the young man began to recover. After rehabilitation he completed high school and was described as "85 percent back to normal." The physician commented, "I've never seen anyone in as bad a shape as he was make it. That's a miracle."

Table 2. Age Groups of Patients Undergoing CPR in Three Television Series.

Series	Child	Teenager	Young Adult	Middle-Aged Adult	Elderly Person	Total
			number of cases (percent)			
Chicago Hope	2	2	1	5	1	11
ER	5	7	9	7	3	31
Rescue 911	9	1	3	3	2	18
Total	16 (27)	10 (17)	13 (22)	15 (25)	6 (10)	60

Discussion

Patients participate in decisions about their care today as never before. As the physician–patient relationship has evolved into a collaborative one, patients are expected to digest and evaluate complex information, often at a time of great emotional stress. This is particularly true with respect to decisions about the end of life.

Patients have few sources from which to learn about illness and death. Acute illness — and, in particular, terminal illness — is for many people no longer part of everyday life. Therefore, images in the media strongly shape the public's beliefs about medicine, illness, and death.[21] The portrayal of CPR and death on three popular television programs is misleading in a number of ways.

First, these three television programs give a mislead-

ing impression about the kind of people most commonly given CPR. On television, children, teenagers, and young adults accounted for 65 percent of the patients given CPR. Of the total number of deaths on the programs, 83 percent were of nonelderly patients. In fact, cardiac arrest is much more common in the elderly than in children or young adults.

Second, cardiac arrest on television was often due to acute injury, the result of gunshot wounds, motor vehicle accidents, or near-drowning; only 28 percent of the patients had primary cardiac arrests. In real life, 75 to 95 percent of arrests result from underlying cardiac disease.[8,10,19]

Third, CPR succeeded more frequently on television than in the real world as reflected in the medical literature. On all three shows combined, 75 percent of the patients were alive immediately after their cardiac arrests, and 67 percent appeared to survive in the long term. On *Rescue 911,* which focuses on the successes of emergency services, the survival rate after CPR was 100 percent. Of the patients on *ER,* 65 percent survived the initial arrest; three of these patients died before discharge from the hospital. On *Chicago Hope,* 64 percent of the patients given CPR initially survived cardiac arrest, and 36 percent survived to discharge.

Comparing these survival rates with those in the medical literature is problematic, since the patients seen on television differ dramatically from those described in the literature with respect to age, underlying illness, and the cause of cardiac arrest. Nevertheless, we would argue that the survival rates in the medical literature are the figures that ought to be given the most weight by patients and families making decisions about the use of CPR.

Rates of long-term survival after cardiac arrest as reported in the medical literature vary from 2 percent to 30 percent for arrests outside a hospital, and from 6.5 percent to 15 percent for arrests that take place inside a hospital.[6-19] For average elderly patients, the rate of long-term survival after cardiac arrest outside a hospital is probably no better than 5 percent. For arrests due to trauma, the reported survival rates vary from 0 to 30 percent.[22-25] Clearly, the rates on television are significantly higher than even the most favorable data reported in the literature.

Finally, on television, the outcome of CPR was generally portrayed as either full recovery or death. The only case of disability was in the young man who had moderate dysarthria after his inhalation of butane and a cleaning agent. If CPR were a benign, risk-free procedure that offered a good hope of long-term survival in the face of otherwise certain death, few people would ever choose to have medical personnel withhold resuscitation. But controversy surrounds the use of CPR precisely because the procedure can lead to prolonged suffering, severe neurologic damage, or an undignified death.[26] In 97 episodes of these medical dramas and reenactments, such outcomes were never portrayed. CPR on television is given primarily to people suffering from acute illness or injury; the possible outcomes are dichotomized into full recovery or immediate death. By avoiding the portrayal of the full range of possible outcomes of CPR, these programs skirt the complicated ethical issues that physicians, patients, and families need to consider.

In a subtle way, the misrepresentation of CPR on television shows undermines trust in data and fosters trust in miracles. In the stories retold on *Rescue 911,* physicians often predict poor outcomes for patients, while family members voice their hope and, in the end, their joy in the "miracle" of their loved ones' recovery. We acknowledge that this drama produces good television, as evidenced by the large viewing audiences. However, these exceptional cases may encourage the public to disregard the advice of physicians and hope that such a miracle will occur for them as well. Faith is central to our ability to maintain hope in difficult situations and often is an important adjunct to the therapy physicians offer. Belief in miracles, however, can lead to decisions that harm patients. The portrayal of miracles as relatively common events can undermine trust in doctors and data.

Misrepresentations of CPR on television may lead patients to generalize their impressions to CPR in real life. For example, an 85-year-old woman with metastatic breast cancer may believe that CPR can work as well in her situation as it does for the 23-year-old trauma victim on television. Physicians discussing decisions about the end of life with patients and families should be aware that the public has many sources of information about CPR, some of them misleading. To help patients and families make informed decisions, doctors should encourage patients to discuss their impressions of CPR and its chances of success. We should clarify misperceptions, provide actual data on outcomes, and address specifically the differences between CPR as seen on television and CPR as it is experienced by real patients.

There are limitations to our study. First, we looked at only three television programs. We chose these programs because they enjoy enormous popularity and focus on medicine, but the occasional portrayals of CPR elsewhere may be more realistic. Second, this analysis rests on the assumption that the public does not distinguish fact from fiction. Unfortunately, however, an important part of the attraction of these television programs is their realism.[27] In many respects, these programs accurately portray the medical environment. People want to go behind the scenes to see true stories of medicine, and modern television works hard to satisfy this curiosity. Because these shows appear realistic in many respects, the line between fact and fiction is blurred.

What should our response be? Given the media's extraordinary influence, we could hope that the producers of television programs might recognize a civic re-

sponsibility to be more accurate. This may not happen, however. The primary goal of these television series is to entertain, a goal served by the high drama and the promise of hope all three shows offer.

Given this reality, physicians need to recognize and acknowledge the images the media present as we help patients and families make informed decisions about the use of CPR. During discussions about the use of CPR, we should inquire about our patients' perceptions of survival after CPR, specifically address the images of CPR on television, and present quantitative data about possible outcomes to our patients, when appropriate. With these efforts, physicians, patients, and families will be able to make better-informed decisions about these difficult issues.

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REFERENCES

1. The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients: the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). JAMA 1995;274:1591-8.
2. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Making health care decisions: a report on the ethical and legal implications of informed consent in the patient-practitioner relationship. Washington, D.C.: Government Printing Office, 1982.
3. Schonwetter RS, Walker RM, Kramer DR, Robinson BE. Resuscitation decision making in the elderly: the value of outcome data. J Gen Intern Med 1993;8:295-300.
4. Schonwetter RS, Teasdale TA, Taffet G, Robinson BE, Luchi RJ. Educating the elderly: cardiopulmonary resuscitation decisions before and after intervention. J Am Geriatr Soc 1991;39:372-7.
5. Murphy DJ, Burrows D, Santilli S, et al. The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation. N Engl J Med 1994;330:545-9.
6. Murphy DJ, Murray AM, Robinson BE, Campion EW. Outcomes of cardiopulmonary resuscitation in the elderly. Ann Intern Med 1989;111:199-205.
7. Eisenberg MS, Bergner L, Hallstrom A. Out-of-hospital cardiac arrest: improved survival with paramedic services. Lancet 1980;1:812-5.
8. Roth R, Stewart RD, Rogers K, Cannon GM. Out-of-hospital cardiac arrest: factors associated with survival. Ann Emerg Med 1984;13:237-43.
9. Guzy PM, Pearce ML, Greenfield S. The survival benefit of bystander cardiopulmonary resuscitation in a paramedic served metropolitan area. Am J Public Health 1983;73:766-9.
10. Eisenberg M, Bergner L, Hallstrom A. Paramedic programs and out-of-hospital cardiac arrest. I. Factors associated with successful resuscitation. Am J Public Health 1979;69:30-8.
11. Longstreth WT Jr, Cobb LA, Fahrenbruch CE, Copass MK. Does age affect outcomes of out-of-hospital cardiopulmonary resuscitation? JAMA 1990; 264:2109-10.
12. Taffet GE, Teasdale TA, Luchi RJ. In-hospital cardiopulmonary resuscitation. JAMA 1988;260:2069-72.
13. Tresch DD, Thakur R, Hoffmann RG, Brooks HL. Comparison of outcome of resuscitation of out-of-hospital cardiac arrest in persons younger and older than 70 years of age. Am J Cardiol 1988;61:1120-2.
14. Tresch DD, Thakur RK, Hoffmann RG, Aufderheide TP, Brooks HL. Comparison of outcome of paramedic-witnessed cardiac arrest in patients younger and older than 70 years. Am J Cardiol 1990;65:453-7.
15. Vertesi L, Wilson L, Glick N. Cardiac arrest: comparison of paramedic and conventional ambulance services. Can Med Assoc J 1983;128:809-12.
16. Eisenberg MS, Bergner L, Hallstrom A. Cardiac resuscitation in the community: importance of rapid provision and implications for program planning. JAMA 1979;241:1905-7.
17. Bedell SE, Delbanco TL, Cook EF, Epstein FH. Survival after cardiopulmonary resuscitation in the hospital. N Engl J Med 1983;309:569-76.
18. Karetzky M, Zubair M, Parikh J. Cardiopulmonary resuscitation in intensive care unit and non-intensive care unit patients: immediate and long-term survival. Arch Intern Med 1995;155:1277-80.
19. Becker LB, Ostrander MPO, Barrett J, Kondos GT. Outcome of CPR in a large metropolitan area — where are the survivors? Ann Emerg Med 1991; 20:355-61.
20. Edgren E, Hedstrand U, Kelsey S, Sutton-Tyrrell K, Safar P. Assessment of neurological prognosis in comatose survivors of cardiac arrest: BRCT I Study Group. Lancet 1994;343:1055-9.
21. Turow J. Playing doctor: television, storytelling, and medical power. New York: Oxford University Press, 1989.
22. Aprahamian C, Darin JC, Thompson BM, Mateer JR, Tucker JF. Traumatic cardiac arrests: scope of paramedic services. Ann Emerg Med 1985;14: 583-6.
23. Copass MK, Oreskovich MR, Bladergroen MR, Carrico CJ. Prehospital cardiopulmonary resuscitation of the critically injured patient. Am J Surg 1984;148:20-6.
24. Rosemurgy AS, Norris PA, Olson SM, Hurst JM, Albrink MH. Prehospital traumatic cardiac arrest: the cost of futility. J Trauma 1993;35:468-74.
25. Pons PT, Honigman B, Moore EE, Rosen P, Antuna B, Dennocoeur J. Prehospital advanced trauma life support for critical penetrating wounds to the thorax and abdomen. J Trauma 1985;25:828-32.
26. Lavelle JM, Shaw KN. Near drowning: is emergency department cardiopulmonary resuscitation or intensive care unit cerebral resuscitation indicated? Crit Care Med 1993;21:368-73.
27. Annas GJ. Sex, money, and bioethics: watching *ER* and *Chicago Hope.* Hastings Cent Rep 1995;25(5):40-3.

When All You Have Is Quality of Life — Making Medical

Decisions in the Face of Uncertainty

Meghan C. Halley, Ph.D.

When All You Have Is Quality of Life — Making Medical Decisions in the Face of Uncertainty

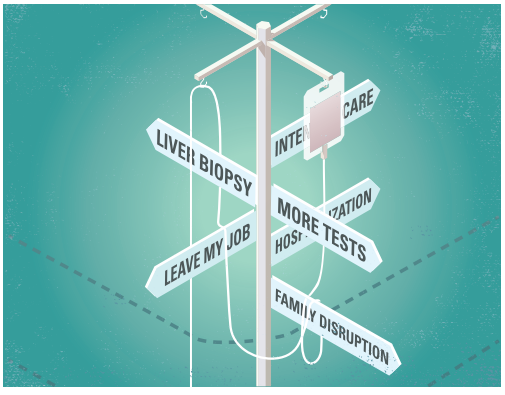
Meghan C. Halley, Ph.D.

"Philip's labs are high again. We would like to schedule a biopsy for tomorrow morning. Come to the hospital this evening so we can monitor his blood sugar while he is NPO before the procedure. Afterward, we will need to monitor him overnight for bleeding. Hopefully it's not rejection, and you can go home in 3 days. Does that work for you?"

For many parents and clinicians, the question posed by our transplant coordinator might seem rhetorical, obviating the need for even a simple "yes." But in my personal and professional experience, the answer is far from simple, and treating it as rhetorical obscures considerations that are essential to the health and well-being of the patient and his or her family. Namely, we — patients, caregivers, and clinicians — too often approach medical decisions without sufficiently considering the uncertainty surrounding the potential benefits of these choices or the potential risks of the cumulative impact of these decisions on patients' and families' quality of life.

I am a medical anthropologist and health services researcher whose work has focused on understanding and supporting patients and families who are making complex health care decisions. I have authored papers and led studies focused on shared decision making, doctor–patient communication, and the development and testing of decision aids and other decision-support interventions. I am knowledgeable about the literature on strategies for effective medical decision making and about the benefits of patient engagement for both patients and clinicians.

I am also the parent of an adorable medical mystery of a 5-year-old named Philip who, in his short life, has endured multiple bowel obstructions, meconium pseudocyst, biliary atresia, an ischemic stroke, a liver transplantation, hypertension, glycemic instability, and post-transplantation lymphoproliferative disease, among other problems. He spent most of the first 7 months of his life in the ICU, and my husband and I estimate that he has — and therefore we have — spent at least half his life in a hospital, doctor's office, or lab. At the age of 3, Philip was enrolled in the Undiagnosed Diseases Network, whose elite physician researchers remain convinced that his symptoms are due to a rare genetic disorder that currently remains beyond the limits of medical knowledge.



In this morass of medical uncertainty, I must repeatedly answer the question, "How do I decide what is best for my son?" Despite (or perhaps because of) my having exactly the type of professional training that should help me answer this question, I have found myself more bewildered than empowered in trying to make medical decisions for Philip. Without a diagnosis, I repeatedly find that I lack clear parameters for understanding treatment choices, for weighing risks and benefits, and for drawing on existing data to inform these decisions. This uncertainty is exacerbated by the relentless barrage of decisions, large and small, that I must make, with no true north from which to find my bearings. Furthermore, the consequences of these myriad decisions are experienced not as isolated, but as cumulative, in terms of their effects on both Philip's development and his and our family's quality of life. These two elements of medical decision making — the uncertainty underlying it and its consequences for quality of life — are important in many instances, but they are essential in the context of undiagnosed disease. In the face of the disorienting uncertainty inherent in making decisions for Philip, quality of life has been my only compass.

For Philip, then, a proposed liver biopsy in response to elevated liver-function tests may, in isolation, seem like a reasonable choice with some small risks (bleeding and side effects of anesthesia, both rare) and the potential benefit of catching rejection early. However, this calculation does not account for the fact that Philip's liver numbers bounce around constantly for reasons that no one understands, making biopsy a frequent consideration. It also does not take into consideration that he has already endured three hospitalizations for truly urgent issues in the past 2 months, each of which has financial, physical, psychological, and developmental effects on Philip and our family. Thus, the risk–benefit calculation for this biopsy is not just for this biopsy: it includes the risk of never saying no to more tests, more procedures, more days in the hospital, all for the benefit of fighting a disease that cannot be named. And the consequences of this endless medical journey continue to accumulate until, for example, a parent finally has to leave a job,

a sibling starts to show signs of serious emotional problems due to persistent family disruption, or the sick child adds global developmental delay to his already long list of diagnoses.

I do not in any way intend to suggest that clinicians should have a different standard for recommending care for patients with undiagnosed diseases. Physicians should and must tell their patients and their families what they think is medically best in any given situation on the basis of the available evidence. I also do not feel that recognition of medical uncertainty and likely effects on quality of life need to be the only factors driving medical decision making for patients with undiagnosed disease. Fortunately, in at least a subset of the medical decisions we have faced, many skilled, thoughtful physicians have been able to draw on their deep medical knowledge to provide evidence-based recommendations to mitigate symptoms, even as the exact cause remains unknown. But I would argue that physicians who are more willing to recognize and discuss the role of uncertainty in the recommendations they make regarding their patients' care, and who are willing to keep quality of life at the center of discussions with patients and families, will ultimately do what is best for their patients and their families.

Despite his laundry list of challenges, Philip has been fortunate to receive the majority of his care at one of the most prestigious children's hospitals in the United States, which also happens to be at walking distance from our home. He still takes a medicine cabinet's worth of drugs each day, is followed by an army of specialists, and has no fewer than four medical or therapy appointments each week. But the first thing new care providers invariably say when they meet him is, "I can't believe he looks so good" — and frankly, on most days, neither can I. I remain hopeful that Philip will someday have a diagnosis. But in the meantime, I will continue to try to make the best decisions I can to ensure that he and our family have a life.

Disclosure forms provided by the author are available at NEJM.org.

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Limiting Treatment in a Social Vacuum

A Greek Chorus for William T.

Kathryn Montgomery Hunter, PhD

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Decisions about the fate of irreversibly incompetent patients, troubling even in the absence of financial constraints, pose problems that are larger than simply medical or legal and require broader social attention. These decisions depend on a social and individual history to which the patient's family and friends customarily offer a guide. But

See also p 713.

who supplies the answers when the patient, suddenly incompetent, exists in a social vacuum, without friends or family or recorded wishes? It is still necessary to decide how the abstract principles of law and ethics are to be applied in a particular case; with increasing pressure not to spend money needlessly, medicine stands in need of a process or ritual that will preserve the physician-patient relationship and protect both parties from arbitrarily applied rules.

THE CASE OF WILLIAM T.

William T. was a sadly ordinary patient whose case illustrates the difficulties of determining the care to be given to an incompetent patient in the absence of a family. At the time of his admission to the hospital he looked younger than his 28 years, although he had been a heavy drinker since the age of 16 years. After a partial pancreatectomy five years before, he became insulin dependent, and his medical record described him as poorly compliant "with frequent visits to emergency rooms . . . after . . . missing his injections." One morning he was found in a nearby park unconscious and having seizures, and tests in the emergency room showed that he was severely hypoglycemic and hypoxic. Perhaps he had overdosed on his insulin. Except for erratic twitches he did not move, and he did not respond to deep pain. His electroencephalogram (EEG) was flat.

William's family situation was as bleak as his prognosis. His mother was dead, his father in failing health in a distant state. There had been little contact between them since William's childhood, and though his father was saddened when he was told of William's condition, he was not in a position to take an active role in decisions about his son's treatment. A younger male cousin, with whom William had lived years before when he first moved to the city, visited twice, but he did not want to be responsible for William and did not return.

With difficulty the staff restored William's blood glucose level and stopped his seizures. They placed him on a respirator from which some time later he was easily weaned. After six weeks in the hospital he seemed to have established cycles of sleep and wakefulness, although he was not conscious. He yawned and blinked and withdrew from deep pain, but his EEGs still showed no cortical activity and his arms had begun to contract. He was considered to be in a persistent vegetative state, described by neurologists as an intermediate state between coma and consciousness from which in the first few days and weeks a patient may emerge.[1] But unlike coma, from which patients have been known to wake after years, a persistent vegetative state beyond a month's time is regarded as irreversible. Heart and lungs function normally because the patient is not entirely "brain dead," but only these subcortical activities continue. William had every prospect of living on and on, unresponsive and unknowing.

What was to be done? For the first month he was in the hospital, William had been the classic case of the last bed in the intensive care unit. The house staff grew tense and some were angry. What if a youngish family man with a heart attack were brought in? William's chart was marked "DNR"—do not resuscitate. But someone so young was unlikely to need cardiopulmonary resuscitation. Ironically, his heart and lungs were working well.

DIFFICULT DECISIONS

Should he be treated for infection? He had been given intravenous (IV) antibiotics since admission, and in the fifth week, when he developed a *Candida* septicemia, he was treated with amphotericin B for 12 days. The attending physicians expressed some doubt about the wisdom of starting this last treatment, saying they wished they had been consulted specifically on that issue, even in the middle of the night. But they had not limited treatment beyond the DNR order before the *Candida* infection was diagnosed and they did not stop the amphotericin B (or the earlier penicillin) once it was begun.

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What would William himself have wanted? No one knew. The resident who had taken care of him in the clinic reported that she had once told him that she doubted that he would live five years at the rate he was going—always drunk, taking his insulin erratically, leaving detoxification programs only to turn up soon afterward in soup kitchens and flophouses—and that he had answered that he did not want to die.

She described him as "passive and manipulative," unable to follow through with any of the plans she devised for him. Yet, she wrote, she came to like him. He was gentle and humorous and told "great stories about working in the saw mills in the South." She had difficulty deciding on the DNR order for William T., comparing him to a young woman who had a prolonged cardiopulmonary arrest from a pulmonary embolus after childbirth. The resident reported that she had had "no trouble deciding that [that patient] would have no 'aggressive' interventions and that she shouldn't be supported if complications arose, and that she be permitted to die." Even though the young mother suffered "through no fault of her own and had so much reason to live," the resident felt differently about William. "I'd known him before," she wrote, "and I could almost imagine him waking up as he lay in bed. I knew that logically it was very unlikely that he would ever regain consciousness and even less likely that he could return to any independent level of function, but it was hard to think about abandoning him. In the end, I decided that it would be for the best not to support him vigorously, but it was not a simple decision."

The nurses had trouble, too. As William improved, breathing readily on his own, beginning to respond to deep pain, and even occasionally seeming to "see" during his "waking" cycles, several of the nurses began to feel uneasy with the DNR order. Like the resident, they were about William's age, and they began to feel that they knew him.

Nor were they alone. After six weeks' time, William's case and William himself were brought to grand rounds, and the psychiatrist invited to participate asked that William be taken from the room. "I'm sure if I had taken care of him as long as many of you have," he said apologetically after William was taken back to his room, "I would be confident that he could not understand what we are saying about him. But as it is, I was not comfortable speaking in front of him." For William had seemed quite ordinary, sitting almost upright in the bed, his IV pole alongside, twitching occasionally in a palsied way. Seen in profile he seemed to be scanning the large audience for someone he knew or who might know him.

The problem of what was to be done for William was compounded by the question of how to decide it. In the absence of a mother or sibling or friend able to say either "William would never have wanted to go on like this" or "William was not a quitter," how could a decision about limiting treatment be made? The lack of a family might doom William to a long life as an unseeing, unknowing, all but unfeeling medical object. Equally likely, he was at risk for neglect, either unintentional and "benign" or as the object of administrative rules. No matter what they chose to do or not to do (or failed to choose to do or not to do), how could those taking care of William believe they had done the right thing—or even a good thing—for him?

THE GREEK CHORUS

In the absence of a family, some semblance of a community was necessary both to protect William T. and to buffer his caretakers from social and administrative pressures. Something more than a consideration of ethical and legal principles was needed, something prior to rational disciplines and more amenable to the individual and the empirical. A process or a ritual seemed best, and the discussion at grand rounds, formal and agonized, suggested the model of the Greek chorus.

Greek tragedy is about human fate, which is to die. Its heroes are caught in crises that neither logic nor good intentions can remedy. There is no sense in Oedipus' saying, "I didn't mean to do it." That is precisely tragedy's point. The innocence of his motives is a given: didn't he as a young man leave his adoptive parents' home to escape the prophecy that he would murder his father and lie with his mother? Sophocles' Antigone tries to persuade her uncle, Creon, that her religious duty to bury her brother is a higher duty than obeying his decree forbidding the burial of traitors. But if Creon were to change his mind about the duty, shared by rulers and their nieces, to obey the laws of the state, where then would social order be? Orestes, in Aeschylus' trilogy of tragedies, might be deterred from killing his mother Clytemnestra, but then his father's death at her hands would go unavenged. In these tight places, with the human condition drawn into a noose, the chorus steps forward, spectator-actors, participant-observers, quasi-characters who speak as one to the audience or, through their leader, to the principal characters.

The Greek chorus takes no action. Readers of the plays are often impatient with the choral "interruption" for just this reason, but drama as we understand it, the interaction of individuals, grew out of the choral odes. Historically, principal roles developed from "solos," which interrupted the odes, and grew in number and importance with each tragedian from Aeschylus to Euripides.[2,3] Instead of action, the chorus offers advice and history and support for the protagonist. It is made up of citizens, as in *Oedipus;* they are often old, like the men left behind in *Agamemnon* when the younger men set sail for Troy. They remember: they sing of Agamemnon's fatal sacrifice of his daughter to change the wind ten years before, or they recall the day Oedipus came to Thebes and won the queen's hand by answering the riddle of the Sphinx. They are traditional moralists; they think and feel in clichés, they utter common wisdom. This is seldom any material help to the hero, for it is the nature of tragedy to enact crises about which common wisdom may be uttered on both sides. When Creon argues for the rule of law in the city-state, a rule of law operating impartially as the source of society's stability and its ruler's virtue—even when the king's niece claims to be following her conscience—the chorus, made up of good citizens, agrees. But when Haemon, Creon's son and Antigone's beloved, argues her case (and his own) before his father, the chorus, as devout as it is patriotic, sees the rightness of religious duty, too.

The chorus, then, establishes a moral resonance for the hero's fate. Its virtue is its presence and its sympathy and its clear meditation on his or her predicament in a social and historical context. The hero cannot "win" in tragedy either because two right courses of action conflict or because the hero's fate is inexorably determined. It is not the chorus's job to choose for the hero. Instead it must present the conflict, agonize over its consequences for the hero and the community, reflect on its history and its moral significance, pointing to its inevitability, in light of all that has gone before. The hero, whatever course is chosen, whatever fate unrolls, bears the burden of what is left undone, the right course of action not chosen. The chorus will remain and remember; its last ode will close the play. Beyond the tragic ending, we imagine, the chorus will store up the memory of the struggle just ended, and this will in its turn be the stuff of moral reflection on some future occasion. This is part of

the genius of Greek tragedy, for we sense that the conflicts have been met only for this individual case. They remain and will recur.

ASSEMBLY AND FUNCTION OF A "CHORUS"

In William's predicament a family or close friends would have provided such a chorus, and fortunately in most crises in medical care this is just the case. In the absence of a family, however, others will fill the role of a chorus. Just as performance in the chorus in Athens in the fifth and fourth centuries BC was a citizen's public duty, so a Greek-chorus consultation may be regarded as a part of professional duty. Rather than leaving it to chance to determine who will straggle onto the stage with an unclear apprehension of the moral role to be played or of the case in question and begin to pass judgment, it seems wise to assemble a chorus from those who know the patient best. Those staff members who have taken care of William should be asked to reflect on the courses of action open to William's physicians in the present case. Those who know the patient best will vary, but a typical chorus when there is no family or close friend, as in William's case, will be made up of the attending physicians, the consultants in neurology, psychiatry, and ethics, a lawyer, a chaplain, but first and foremost the residents and nurses who had taken care of him from the beginning. Their duty for the moment is not to provide an answer, but to set forth the alternatives fully and to struggle with them, considering them in the context of William's life and his society.

Such a conference differs from the ordinary hospital ethics committee in two ways: in its temporary, ad hoc charge and in its involvement of the patient's caretakers. Occasionally it is argued that decisions to limit treatment are best made by an impartial group composed of people who do not know the patient and who therefore can reach an objective decision. Certainly an impartial standing committee with a stable membership is wise when access to rationed resources is at issue. As William's resident noted, it is always easier to say no to an unknown person. But, however fair the method, it is inappropriate in a situation where there is no quota, where patients will not be denied treatment if they need it. Above all, an impartial committee reaching an objective decision is alien to the philosophical basis of medical practice. Triage is a battlefield concept applicable in times of great need and great scarcity, but medicine remains founded on a one-to-one relationship intended to help the patient.

A Greek chorus should be assembled, then, not only for William but for the profession and its practitioners. It might be called "management rounds," since a "Greek chorus" is a title better suited to essays than to hospital schedules. Such a conference provides an opportunity for residents and students to reflect on the relation between society and the medicine they are learning and to clarify economic rumor and imperfectly perceived administrative policy. On the patient's behalf it creates for the moment a sense of community, because, unaided by a family, the staff must act both for the patient and for society without knowing which side of the question either would favor.

A chorus would not discover new facts, either medical or social, that could resolve the quandary. Presumably by this time all facts are known. Nor is the chorus intended to reach a decision. A decision will be made, ultimately, by William T.'s attending physician. But the chorus must advise, must air the issues, must come together—like a Quaker meeting or a National Institutes of Health consensus group—to state what seems to be the obvious predicament, its possible solutions, and the nature of the reservations about each of them. It must take account of conflicting opinion, divergent principles, and strong feelings. It must acknowledge emotional attachments or their absence. It must ignore temporarily some of the hospital hierarchy while everyone speaks on one side or the other.

The focus of the chorus will not be legal. Facts of law need to be considered, of course, and a lawyer should be among those assembled, for the law customarily addresses questions more or less like these. But discussions of law and medicine concerned with a single case tend to degenerate into protective maneuvers, ignoring important ethical and emotional issues. This occasion should not be regarded merely as a good hedge against the possibility of a suit. It may well be such a hedge, because no one will regard a decision based on this conference to be hastily or arbitrarily made, but a quicker consultation between physicians would be sufficient for the requirements of the law.

Nor should the focus be on ethical principles, although certainly ethics must be discussed. Some residents, alarmed by generalized admonitions about the cost of medical care, questioned the value of continuing to take care of William T. He occupied a valuable bed in a community that had controlled its hospital capacity; it would be at least eight months until he could be transferred to the long-term care hospital. Was there, they wondered, a duty to society to limit care in William's case? The answer to this is clear. There was no uniform, socially agreed on limitation such as the de facto dialysis policy in the United Kingdom or the rules for amniocentesis in Canada. There were no triage policies drawn up by the hospital or the state. The staff had not established criteria for admission and release from the ICU,[4] and the hospital had not yet worked out a statement on levels of care.[5] Nothing other than the hesitations and worries of the residents suggested anything other than what had been done: resuscitation, intensive care for a prolonged period, and antibiotics for infections, all at public expense and in democratic, first-come, first-served order.[6] As citizens, according to their views, the staff might want to press for rules that would expand care available in the community or for restrictions on care for the irreversibly incompetent. As employees in that particular hospital they might want to work for clear guidelines or more beds. But as William's caretakers their duty was to him: to prevent his suffering and to prolong his life by ordinary means.

But what are "ordinary means"? Ethical considerations clarify, but they do not provide definitions in context or answers in equally weighted dilemmas. People provide these answers, and of necessity not always on rational grounds. It will be important for the Greek chorus to discuss rights and obligations and utility. But no agreement about William is likely to be reached by means of rational abstractions any more than on the question of abortion. The question of personhood is much the same. Is William T. a person? Nurses feel a patient-practitioner relationship that makes them reluctant to have him "no-coded" or his chart marked "DNR." The resident speaks of not wanting to "abandon" him, implying clearly that some part of the historical William still remains to receive her care. If we grant that for these people a person, William T., exists, how much care is consistent with what all agree is a permanently diminished personhood? And what is owed William once the resident is no longer on the service and he is cared for by a new resident who doesn't know him—as the first resident had not known the young mother with the pulmonary embolus? What if William stops appearing to look about him in his "waking" state and the nurses no longer sense that someone, a person, inhabits an increasingly drawn and purposeless body?

Even if the questions of personhood could be given a stable answer and were not subject to all the errors and fallibilities of perception, how would these determinations translate reliably into specific medical treatment? A utilitarian assessment would seem to have us stopping William's insulin promptly, but the greater good might be served by a William who represents—and goes on and on into the future representing—all the evil and mischance that can befall a human being in his particular circumstances: a man born black and poor in the United States in 1954.

For William's life must also be taken into account by the chorus. They must reflect on the individual's moral trajectory in the time and place and family circumstances that have been his lot. Facts are missing. But just as the citizens of Thebes knew some but not all of Oedipus' story, just as the left-at-home old men climbed the battlements to descry the signal fires lit on hills from Mycenae to Troy, so we can reconstruct William's story, restoring and re-storying him.

He was born black in the American South ten years before the civil rights bill was passed into law. His parents separated; he left his birthplace. He went North, participating in one of the mythic patterns of American, indeed Judeo-Christian, experience: an exodus in search of a promised land. It is a story told and retold in our novels and films as well as in sermons and family stories. But it didn't work out. William lost contact with his family; he was lost to work and friends and a home before he was through adolescence. He killed the pain with alcohol. His body began to fail: pancreatitis and alcoholic hepatitis developed. He compounded the failure with inattention and abuse. He hoped for rescue but lacked strength to manage it himself. He forgot his insulin for days, then took it all at once to make up. He didn't mean to die.

CONCLUSION

Without a clear economic imperative that establishes limits to the medical services society provides, the medical profession faces an imprecisely defined need to cut costs, and it has few guides[7] for moderating the activist life-at-any-cost ethic that has traditionally informed medical education and practice. Instead of asking residents to triage patients or to meet criteria for a fixed quota system, we are asking them to play a major part in a more difficult endeavor: the redefinition of good medical practice. Much of this will be a relief rather than a burden, for the acceptance of such ideas as palliative care, alternatives to hospital care for the dying, and the patient's right to refuse or limit treatment will benefit patients, their families, physicians, and society at large. But the role of gatekeeper conflicts with the physician's duty to the patient.

William T.'s life intersects the lives of those who hoped to cure, who never meant to become gatekeepers to medical care or arbiters of death. Some of them believe their care was wasted on William; some believe it was their duty. Some believe both things at once. For their own well-being and the well-being of their profession, a ritual that takes note of these intersecting lives and crossed purposes is required. We cannot ask for one better than that which served Sophocles and his inescapably tragic view of human life.

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References

1. Plum F, Posner JB: *The Diagnosis of Stupor and Coma*, Contemporary Neurology Series, No. 19, ed 3. Philadelphia, FA Davis Co, 1980, pp 6-7.
2. Harrison JE: *Themis, With an Excursus on the Ritual Forms Preserved in Greek Tragedy by Gilbert Murray.* Cambridge, England, Cambridge University Press, 1912.
3. Pickard A: *Dithyramb Tragedy and Comedy*, Webster TBL (revised ed). Oxford, England, Clarendon Press, 1962.
4. Detsky AS, Stricker SC, Mulley AG, et al: Prognosis, survival, and the expenditure of hospital resources for patients in an intensive care unit. *N Engl J Med* 1981;305:667-672.
5. Optimum care for hopelessly ill patients: A report of the Clinical Care Committee of the Massachusetts General Hospital. *N Engl J Med* 1976;295:362-364.
6. Bayer R, Callahan D, Fletcher J, et al: The care of the terminally ill: Morality and economics. *N Engl J Med* 1983;309:1490-1494.
7. Wanzer SH, Adelstein SJ, Cranford RE, et al: The physician's responsibility toward hopelessly ill patients. *N Engl J Med* 1984;310:955-959.

The Progression of Medicine

From Physician Paternalism to

Patient Autonomy to Bureaucratic Parsimony

Mark Siegler, MD

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The language used to describe the practice of medicine and the metaphors employed to depict the relationship of patients and physicians establish conceptual boundaries for such discussions and affect the practices themselves. My colleague, James Gustafson, PhD, made a similar point recently:

> How the medical staff or the ethician describes persons and their relations to each other [ie, whether as ". . . individual contractors or persons in patterns and processes of interdependence . . ."] is a matter of critical judgment. The alternative descriptions back alternative ways of construing the moral situation. How that situation is construed confines or enlarges the morally relevant features to be taken into account in patient care [unpublished work, 1984].

In recent years, medical practice has been regarded (at least by most medical ethicists and by lawyers) primarily as an impersonal encounter between two isolated and autonomous persons—the patient and the physician—whose individual interests were to be rigorously protected from each other by rules and procedural standards. This view of medicine has generated a variety of legislative and judicial initiatives intended to protect patients from physicians. It also has determined what factors were morally relevant and, in turn, what sorts of medical actions were considered moral or immoral. This narrow, limited, and somewhat sterile conception of medicine is now changing.

See also p 716.

It is not surprising that this view never caught on with physicians and patients; it was wrong. It failed to describe the extent or complexity of the interactions that surfaced when a previously healthy individual became ill. Thus, it failed to take account of the relationship of the ill person to family and friends as well as to the physician; it also disregarded the physician's relationship to colleagues, the health care team, the institution, and society.

In this issue of the ARCHIVES, Kathryn Hunter, PhD, a sensitive observer of the medical system, describes a case that illustrates the subtlety and difficulty of reaching good (and therefore morally appropriate) clinical decisions.[1] The metaphors of autonomy and paternalism are not sufficient to capture the complexity of the relationship of the patient to the health team; simplistic decision procedures are also found wanting. Dr Hunter recognizes that the world of medicine is a world filled with technical and human details. Decision making is a process, not an act. Moral rightness depends not only upon procedural guarantees but upon knowing all that is relevant about the patient who is receiving care and in acting rightly based upon that knowledge.

As a procedure for reaching good decisions, Dr Hunter suggests the elegant image of a Greek chorus, as represented, for example, in the plays of Sophocles. At first glance, this seems a burdensome and inefficient suggestion. Imagine a group of white-robed individuals swaying rhythmically to the clinical fortune of a seriously ill patient: expressing happiness and pleasure when the patient appears to be improving and speaking gloomily when the patient's condition deteriorates. On further reflection, however, it appears that the suggestion may not be quite so unreasonable. In fact, it may describe our hospital care system as it currently exists. Even in the hospital setting, the principal players in the drama, the physician and patient, are cushioned or buffeted from all sides by community interests that include the patient's family and friends and the house staff, the nursing staff, medical consultants, chaplains, social workers, dieticians, and hospital administrators.

Those of us who have cared for severely ill patients realize that life-and-death decisions are not reached secretly in back rooms but are arrived at through an ongoing process of discussion, reflection, and consideration, which yields a temporary conclusion that will more than likely be modified in the face of changes in the patient's condition. Most medical decisions are neither private nor irrevocable; they tend to be public and are open always to reassessment. Health professionals and the patient's family and friends together play the part of a modern-day chorus, sometimes supporting difficult decisions and other times criticizing them for technical mistakes or narrowness of vision.

PATERNALISM AND AUTONOMY

For the past 20 years, the field of bioethics has been concerned with one issue more than any other: the proper relationship between physician paternalism and patient autonomy in medical practice. This tension between autonomy and paternalism has reverberated in discussions rang-

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ing from informed consent to appropriate care for dying patients to ethically acceptable models of the physician-patient relationship. This issue was the dominating motif in the work of two recent national bioethics commissions. The modern medical era, which began triumphantly after World War II and which is now coming to an end, might be called *the Age of Autonomy*. This emphasis on autonomy was sparked by widespread political and social movements to gain entitlements and rights, to achieve equity and equality in the distribution of health services, and to dissolve the hierarchical barriers (often believed by critics of medicine to be artificial and power-oriented barriers) between the patient and the physician.

The central question that has occupied a generation of American bioethicists has been this: *Procedurally*, where should decision-making power reside, with the physician or with the patient? A quite different question, and one that has been of much greater concern to clinicians than ethicists, is this: What is the right and good decision for this particular patient in these clinical circumstances? In the bioethics literature, however, ideas of right and good decisions often have been subordinated to *procedural standards*—the allocation of power—by which such decisions are reached. In this latter view, a "good and right" decision is one that pays sufficient heed to the wishes and presumed values of the patient—that is, one that "respects the person"—even if the patient's health problems may be so severe as to limit his or her capacity to make crucial, and at times life-and-death, decisions. "Good and right" decisions, in this view, are less concerned with outcome, or with the patient's "best medical interests," than they are with the process of respecting the patient's right to control what is done to his or her body.

By contrast, traditional paternalism in medicine assigned considerable moral authority and discretion to physicians because good health was assumed to be a value shared by the patient and the physician and because physicians' competence, skills, and ability placed them in a position to help patients regain good health. This model emphasized patient care rather than patient wishes, patient needs rather than their "rights," and physician discretion rather than patient autonomy or self-determination. The central issue in a pluralistic society such as ours, and the issue that has engaged bioethicists for the past 20 years, is this: Under what circumstances can one justify paternalistic actions, which at times might ignore patients' wishes in order to save their lives? A brief review of the history of the physician-patient relationship may illuminate the question.

THREE AGES OF MEDICINE: A PROGRESSION IF NOT "PROGRESS"

The history of the physician-patient relationship in Western medicine can be divided into three periods: *the Age of Paternalism*, *the Age of Autonomy*, and *the Age of Bureaucracy*.

The Age of Paternalism lasted thousands of years and represented the basic authoritarian and sacerdotal strain in medicine. The bond between patient and physician was dyadic and few outsiders could penetrate into this personal, magical realm of healing. This model of medicine—the "doctor knows best" model—was premised on trust in the physician's technical skills and moral stature, was buttressed by an attribution of magical powers to the healer, and was characterized by patient dependency and physician control.

Medical achievements during this lengthy period were rather modest. In fact, this medical system was relatively cheap and relatively ineffective. It provided symptomatic care rather than cure; it emphasized the power of information (the prognosis), which was a mystery known only to the trained physician and imparted in measured doses to the patient; it was able to deal better with psychological than with physical aspects of disease; and it taught principles of hygiene and preventive health care. In this system, the physician was the source of information, psychological support, and symptomatic relief. In light of our modern ideas of pathophysiologic medicine and of immensely effective medical and surgical therapies, we are often struck by how long this older and much less effective medical system held sway over the minds and bodies of men and women. We are thus forced to realize that for all its limitations, this traditional and relatively ineffective system of healing must have addressed and satisfied many basic human needs for the multitude of patients it served.

The Age of Autonomy, by contrast, lasted at most 40 years (1945 to the present) and, more likely, just 20 years (1965 to the present). Technically, it was an age of extraordinary advances in the understanding of physiologic and biochemical mechanisms of disease, and in the development of remarkable and often very expensive medical and surgical therapies for disease. It was a medical epoch that focused on disease. It emphasized treatment rather than prevention, cure rather than care. Cost was not seen as a relevant factor and certainly not one to be taken account of when juxtaposed against patient autonomy, patient need, or even patient desire.

During this period, the dyadic relationship between physician and patient was maintained, but the theoretical balance of power was shifting subtly from physician to patient. The informed consent legal doctrine, and the potential threat of malpractice suits for battery or negligence against physicians who failed to respect the doctrine, reflected deeper concerns. Many ethicists, legal scholars, and consumer advocates wished to assign patients control over (but not always responsibility for) decisions about their own care. This model emphasized patient education and patient rights. According to this view, practitioners should act as servants to their patients, to transmit medical information and to use clinical skills as the patient directs, without seeking to influence patients' decisions, much less actually making them.

The rhetoric of this period was libertarian and consumerist and the medical air (at least, the air in ivory towers where medical ethicists held court) was filled with cries of "autonomy . . . self-determination . . . patient sovereignty . . . freedom . . . liberty . . ." and the like. The antipaternalist movement reached a peak of sorts when it joined forces with thanatologists to defend the notion of the autonomy of the dying patient and even of those dying patients who were mentally incompetent. The idea here was that even for dying patients who lacked competence, autonomy rather than the medical interests of the patient was the principal ethical ideal to be preserved. This viewpoint led to some strange ideas that are represented, for example, in the report of the President's commission on decisions regarding life-sustaining treatment. Thus, according to the commission, cardiopulmonary resuscitation should be performed on patients who demand it—presumably to acknowledge their autonomy—even if physicians believe, and have so informed the patient, that such an exercise would be futile.[2]

The Age of Bureaucracy has arrived and it is also an Age of Parsimony. This new era will demand cost containment and cost-efficiency and will be based on bureaucratic risk-benefit analyses. Quality of care, always so hard to define, will no longer be an end in itself, but will be balanced against

cost of care, which is much easier to quantify. Tradeoffs will be made. Inexpensive, even if unproved, strategies of care will be promoted by a variety of interest groups. In this new period, dyadic physician-patient relationships will become the exception. The physician will be accountable to multiple interests including employers (health maintenance organizations [HMOs], hospital corporations), hospitals, insurance companies, and government. The physician in the Age of Bureaucracy will have divided allegiances.

In the previous two eras, the patient's "good" was the dominant concern for physicians. In the Age of Paternalism, it was the patient's "best medical interest." In the Age of Autonomy, it was the patient's freedom and right of self-determination. In the new era, however, the patient's good will be balanced against other goods such as the needs of the hospital, the needs of its employees (including physicians), and the needs of society. Decision making no longer will be vested exclusively in the hands of physicians or patients. Physician paternalism and patient autonomy, particularly with respect to medical decisions, will be replaced by institutional and societal efficiency and expediency, based largely on cost concerns. These have emerged as the major elements in decision making. In contrast to the two earlier periods, the wishes of both patients and physicians are already—or will soon be—subservient to the wishes of government bureaucrats, administrators of HMOs, insurance company executives, or corporate vice-presidents of proprietary multihospital chains.

A new medical age is dawning—or has dawned already—but it is not clear that the postmodern age of bureaucratic parsimony will be better than either the old-fashioned age of professional paternalism or the more recent and short-lived age of patient autonomy. The patient and physician fought a battle, which the patient appeared to have won (eg, through the informed consent doctrine), but it was a Pyrrhic victory; in retrospect, it is clear that by becoming antagonists, they both lost. The main hope remaining is that patients and physicians resolve their conflict and that different health professional disciplines resolve theirs and join together again as natural allies—to fight not only the patient's illness but also the society's illness. Together, the physician and patients are a powerful team, who can in one circumstance combat the patient's disease and in another, combat the direction in which health care is headed, toward centralized, bureaucratic control and a resulting loss of autonomy for both physician and patient. This battle must be fought in the political arena, but patients and physicians make up a formidable lobby and one whose concerns would be given a respectful hearing by their political representatives.

INSTITUTIONAL ETHICS COMMITTEE OR GREEK CHORUS

Dr Hunter's suggestion that "management rounds" be organized on each unit rather than for the entire hospital in order to permit "community participation in difficult decisions" is one way to begin the rapprochement of patient and physician. "Management rounds" would represent a kind of Greek chorus, a community of viewpoints that would, in Gustafson's words, ". . . describe persons in patterns and processes of interdependence" (unpublished work, 1984). This metaphor of the Greek chorus is strikingly different from the individualistic language of autonomy and is a more accurate reflection of the multiple interests that enter into difficult medical and ethical decisions. This suggestion also has the advantage of both opening the decision process to involved individuals—professional and lay—and keeping the forum for decisions as close as possible to the actual patient and the immediate nursing unit.

Management rounds, like the Greek chorus, can provide counsel, guidance, and criticism to the protagonist decision maker. But decisions must not be made by a group, just as tragic choices in Greek drama were not made by the chorus. Individuals, not committees, ultimately must choose and must take responsibility for their decisions.

It has recently been suggested by the President's commission and others that hospital ethics committees might help to clarify ethical deliberations and might also improve clinicians' decision making. The precise function of such committees is not entirely clear, but in addition to serving as educational and deliberative bodies, such committees might reach decisions or at least be able to ". . . see that clearly wrong decisions are not permitted."[3] This last suggestion is disquieting. Cassel[4] recently commented on the issue of decision making by committee:

> The coming together of many different perspectives and areas of expertise may provide the "crucible" in which the best (i.e., most humane and most just) decisions are made. But a committee can also provide the setting in which immoral decisions can be made for which no one has ultimate responsibility. This is most likely to occur in a setting where most persons on the committee are relatively removed from the clinical setting, where conflict of interest with administrative needs exists, and where the group dynamic is bureaucratized. Such a committee is no longer a crucible for the tempering of apparently conflicting values, but rather a bureau whose primary value is not the anguish of moral dilemma but the efficiency of decision-making, abiding by rules and adhering to regulations and legal proscriptions.

Currently, hospitals are struggling to develop administrative mechanisms to deal with clinical-ethical concerns, and good ideas deserve a try. The American Hospital Association's recent report, *Guidelines: Hospital Committees on Biomedical Ethics*,[5] encourages considerable flexibility for such committees: "Each institution should take the steps necessary to implement suitable mechanisms that will reasonably provide for sound decision-making practices and for responsible and timely assessment of medical and ethical issues." Perhaps the time is ripe to experiment both with institutional ethics committees and with Dr Hunter's suggestions for Greek choruses (ie, ward management rounds).

Dr Hunter's proposal has considerable appeal. Her suggestion that participation in management rounds be restricted to those individuals involved in a particular case still opens the discussion to many viewpoints—clinical and lay—while limiting the contributions of mere observers and uninvolved moral experts. Furthermore, her idea of many small, local deliberative bodies seems preferable to the notion of single, large, bureaucratic, institution-wide ethics committees. Finally, a Greek chorus that captures the spirit of "persons in patterns and processes of interdependence" may be a sound model to investigate for allocating limited or controversial human and capital resources at the local level.

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References

1. Hunter KM: Limiting treatment in a social vacuum: A Greek chorus for William T. *Arch Intern Med* 1985;145:716-719.
2. *Deciding to Forego Life-Sustaining Treatment.* President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983, p 244, Table 2.
3. Fleischman AR, Murray TH: Ethics committees for infants Doe? *Hastings Cent Rep* 1983;13:5-9.
4. Cassel CK: Deciding to forego life-sustaining treatment: Implications for policy in 1984. *Cardozo Law Review,* in press.
5. *Guidelines: Hospital Committees on Biomedical Ethics.* Chicago, American Hospital Association, 1984.

Substitute Decision Making in End-of-Life Care

Lisa Caulley, M.D., M.P.H.

CLINICAL DECISIONS
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Substitute Decision Making in End-of-Life Care

This interactive feature addresses the approach to a clinical issue. A case vignette is followed by specific options, neither of which can be considered either correct or incorrect. In short essays, experts in the field then argue for each of the options. Readers can participate in forming community opinion by choosing one of the options and, if they like, providing their reasons.

CASE VIGNETTE

A Woman without an Advance Directive

Lisa Caulley, M.D., M.P.H.

Three days ago, you were called to the intensive care unit (ICU) to examine Ms. Smith, a 70-year-old woman who had presented to the emergency department earlier that day with progressive shortness of breath. Ms. Smith had reported fatigue, progressive dyspnea, and intermittent fevers over the previous several days. She had a history of uncontrolled type 2 diabetes. She was accompanied by Ms. Jones, her neighbor and close friend of 10 years. She was febrile (temperature, 39.0°C [102.2°F]) on presentation and had severe dyspnea, with a respiratory rate of 34 breaths per minute. Laboratory investigations showed leukocytosis (19,000 white cells per cubic millimeter), and a chest radiograph showed dense opacities in both lungs. The trachea was intubated immediately, and broad-spectrum antibiotic therapy was initiated. In the ICU, H1N1 influenza was diagnosed on the basis of results of a real-time reverse-transcriptase–polymerase-chain-reaction assay; blood and sputum cultures were positive for *Escherichia coli*. Ms. Smith's condition deteriorated into septic shock, with signs of acute respiratory distress syndrome (ARDS) and acute renal injury.

When you check on Ms. Smith's condition today, you find that despite intensive medical treatment, her condition has not improved. She does not meet clinical criteria for extubation and continues to require ventilatory support; in addition, the ratio of the partial pressure of arterial oxygen to the fraction of inspired oxygen (Pao_2:Fio_2) is falling. Anuria and severe renal dysfunction have developed within the previous 24 hours (estimated glomerular filtration rate, 15 ml per minute), and she has had to undergo dialysis.

Ms. Smith does not have an advance directive. There is no written indication of her wishes, and no designated surrogate decision makers are available to address her goals of care. Her brother, who is her closest family member, has not been in contact with Ms. Smith in more than 20 years. He is uncertain of her end-of-life wishes but is reluctant to consider a "do not resuscitate" (DNR) order. Ms. Jones states that she and Ms. Smith had discussed end-of-life care on several occasions. In speaking with her friend, Ms. Smith had indicated that she would not want life-sustaining measures to be instituted if she were faced with severe critical illness and had said clearly that she would not want to be resuscitated. Ms. Jones feels certain that Ms. Smith would not want resuscitation measures taken.

OPTIONS

Which one of the following approaches would you recommend for this patient? Base your choice on the published literature, your own experience, guidelines, and other sources of information, as appropriate.

1. **Institute a "do not resuscitate" order.**
2. **Continue full resuscitation measures.**

To aid in your decision making, each of these approaches is defended in the following short essays by an expert in the field of medical ethics. Given the situation of this patient and the points made by the experts, which approach would you choose?

OPTION 1

Institute a "Do Not Resuscitate" Order

Muriel R. Gillick, M.D.

Medical decision making is challenging when an incapacitated patient has neither appointed a surrogate decision maker nor drawn up an advance directive. Because Ms. Smith articulated her wishes before she became incapacitated, and because of the overwhelming evidence that cardiopulmonary resuscitation (CPR) would be ineffective, entering a DNR order is appropriate.

The standard of care for ICU physicians is shared decision making,[1] with good decisions having both a technical component and a values component. The technical piece in the case of Ms. Smith involves a summary of her clinical situation and prognosis. As part of shared decision making, the ICU attending physician should explain to the entire care team and to interested parties (in this case, the patient's neighbor and brother) the gravity of the situation and the likely outcome. After the presentation of facts, members of the medical team should express their views of what constitutes reasonable care, to discourage requests for potentially inappropriate treatment.[2] Although current practice is to avoid the term "medical futility" — except in Texas, where the Advance Directives Act allows physicians to withdraw life-sustaining treatment they regard as futile — the team has an obligation to explain that when patients such as Ms. Smith have a cardiac arrest, attempted CPR is almost always ineffective.

The widely accepted framework for the value component of decision making is the use of substituted judgment, or decision making that is based on what the patient would want for herself. The best source of information about the patient's preferences is a written advance directive or the judgment of a surrogate chosen by the patient, but other sources are frequently accepted, including ministers, friends, and neighbors. Although the ICU team should clarify what Ms. Smith understood by "a critical illness" and by "life-sustaining measures," the testimony of Ms. Jones, a neighbor and friend, appears to indicate that Ms. Smith would have favored withholding treatments including, but not limited to, attempted CPR. Since Ms. Smith's brother is uncertain of her wishes, the neighbor's report stands as the best indicator of the patient's wishes.

Although currently, 44 states have "default surrogate consent statutes" that specify who is empowered to make medical decisions for an incompetent adult when no designated guardian or proxy is available[3] (the hierarchy is commonly spouse, adult child, parent, and then adult sibling), Ms. Smith's brother would arguably be disqualified as sole surrogate on the grounds of his 20-year estrangement (with a precedent for disqualification established by laws that exclude divorced spouses from acting as default surrogates). He should be included in the shared decision-making process but should be told that his opinions must rest on substituted judgment, with the relevance of the neighbor's reports explained. A social worker may be helpful in addressing feelings of guilt or anger that might make it difficult for the brother to endorse a DNR order. If Ms. Smith's brother is encumbered by fear that he is contributing to his sister's death, he may opt to defer decision making to the attending physician.[4]

In the rare circumstances in which conflict remains intractable despite technical considerations (the ineffectiveness of CPR, in this situation) and value considerations (the neighbor's testimony), the dispute should be managed by a fair process of conflict resolution. If time pressure prevents further review, the physician may unilaterally enter a DNR order. This decision is consistent with American Heart Association guidelines stating that "clinicians should not hesitate to withdraw support on ethical grounds when functional survival is highly unlikely."[5]

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OPTION 2

Continue Full Resuscitation Measures

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A majority of states have established a surrogate hierarchy in which the highest priority for decision making is given to family members. There

may be a legal justification for designating the patient's brother as the appropriate surrogate, as well as good moral grounds for prioritizing family members over friends as surrogate decision makers. Our most important and deepest commitments are often to family, and there is a presumption that they are likely to choose what is best for the patient.[6] In addition, family members are most likely to be affected by the end-of-life decisions. These are good reasons for designating Ms. Smith's brother as the appropriate decision maker.

When a patient lacks decision-making capacity, we follow a stepwise hierarchy of three standards: first, the patient's advance directive; second, substituted judgment; and third, the patient's best interest. In the absence of an advance directive, applying substituted judgment in practice can be difficult.[7] Although Ms. Jones is certain that Ms. Smith would not want resuscitation measures instituted, empirical research suggests that patients' preferences evolve with their clinical situation.[8] People change their minds and often want to hold onto life at all costs when they are confronted with the real possibility of death. Most seriously ill patients also prefer to have family and physicians participate in resuscitation decisions rather than have their advance directive rigidly followed.[9] Ms. Smith's prior discussion with Ms. Jones may therefore represent a comment that was not fully considered and may not apply to an unforeseen acute event resulting in a brief intubation.

In this case, resuscitation measures should continue for a time-limited trial, for a number of reasons: first, the patient's brother, as a family member, is the appropriate surrogate, and he is reluctant to institute a DNR order; second, Ms. Smith's discussion with Ms. Jones about her end-of-life preferences may not have been fully informed and may not represent Ms. Smith's authentic preference; third, many patients would find it reasonable to accept the trade-off of a brief period of life-sustaining treatment for the possibility of a meaningful recovery from an acute illness; and fourth, Ms. Smith was previously healthy and has no underlying terminal illness that would make continued resuscitation measures futile.

A meeting to clarify the patient's prognosis and the high mortality associated with ARDS and a falling Pao_2:Fio_2 ratio, H1N1 infection, septic shock, and renal failure will prepare her brother to reconsider his decision if Ms. Smith does not begin to show signs of improvement. The case of Ms. Smith is unfortunately all too common. Only 38% of U.S. adults have completed an advance directive.[10] We can ensure respect for patients' authentic preferences and avoid the controversy and angst that were caused in this case by the lack of an advance directive by creating an infrastructure that makes it easy and normative for patients to discuss and document their end-of-life goals, values, and preferences.

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1. Kon AA, Davidson JE, Morrison W, Danis M, White DB. Shared decision making in ICUs: an American College of Critical Care Medicine and American Thoracic Society policy statement. Crit Care Med 2016;44:188-201.
2. Bosslet GT, Pope TM, Rubenfeld GD, et al. An official ATS/AACN/ACP/ESICM/SCCM policy statement: responding to requests for potentially inappropriate treatment in intensive care units. Am J Respir Crit Care Med 2015;191:1318-30.
3. Wynn S. Decisions by surrogates: an overview of surrogate consent laws in the United States. Bifocal 2014;36:10-4.
4. Curtis JR. The use of informed assent in withholding cardiopulmonary resuscitation in the ICU. Virtual Mentor 2012;14:545-50.
5. Mancini ME, Diekema DS, Hoadley TA, et al. Part 3: ethical issues: 2015 American Heart Association guidelines update for cardiopulmonary resuscitation and emergency cardiovascular care. Circulation 2015;132:18 Suppl 2:S383-96.
6. Brock DW. What is the moral authority of family members to act as surrogates for incompetent patients? Milbank Q 1996;74:599-618.
7. Dresser R. Substituted judgment in real life. J Med Ethics 2015;41:731-8.
8. Auriemma CL, Nguyen CA, Bronheim R, et al. Stability of end-of-life preferences: a systematic review of the evidence. JAMA Intern Med 2014;174:1085-92.
9. Puchalski CM, Zhong Z, Jacobs MM, et al. Patients who want their family and physician to make resuscitation decisions for them: observations from SUPPORT and HELP. J Am Geriatr Soc 2000;48:5 Suppl:S84-S90.
10. Yadav KN, Gabler NB, Cooney E, et al. Approximately one in three US adults completes any type of advance directive for end-of-life care. Health Aff (Millwood) 2017;36:1244-51.

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