Editorial

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Improving Care Near the End of Life
Why Is It So Hard?

A 55-year-old smoker with chronic obstructive pulmonary disease develops pneumonia and respiratory failure and is placed on mechanical ventilation. He dies 2 weeks later, after a stormy intensive care unit (ICU) course complicated by gastrointestinal bleeding and septic shock. The next morning, the ICU team questions how such a series of events occur. Although each intervention could be justified as a response to a treatable complication, did the team truly consider the patient's overall prognosis or determine whether he really wanted such aggressive care?

See also p 1581.

The Study to Understand Prognoses and Preferences Outcomes and Risks of Treatments (SUPPORT) interven
described in this issue of THE JOURNAL attempted to prev

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such high-technology deaths. The SUPPORT investigators are to be commended on a rigorous, complex project. Yet, despite their best efforts in this multicenter randomized clinical trial, the intervention failed to improve any of the study outcomes. Why? Like most good clinical research, SUPPORT raises more questions than it answers.

What Is Wrong With Care Near the End of Life?

SUPPORT documented serious problems with terminal care. Patients in the study experienced considerable pain: one half of patients who died had moderate or severe pain during most of their final 3 days of life. Communication between physicians and patients was poor: only 41% of patients in the study reported talking to their physicians about prognosis or about cardiopulmonary resuscitation (CPR). Physicians misunderstood patients' preferences regarding CPR in 80% of cases. Furthermore, physicians did not implement patients' refusal of interventions. When patients wanted CPR withheld, a do-not-resuscitate (DNR) order was never written in about 50% of cases.

Other studies also have found serious deficiencies in pain control and with physician-patient communication. When describing CPR to patients, physicians use jargon, fail to provide quantitative information about outcomes, and miss opportunities to discuss the patient's goals and values. Unrealistically optimistic expectations lead patients to request interventions that physicians believe are inappropriate. Patients have overly optimistic estimates about the outcomes of CPR. After their misunderstandings are corrected, fewer patients desire CPR.

Why Was the SUPPORT Intervention Ineffective?

The SUPPORT intervention provided computer-based projections of survival and functional status to physicians, and skilled nurses attempted to facilitate communication about patient preferences. Why did this intervention fail? For patients to make informed decisions to forgo life-sustaining interventions, several links in a chain of action would need to hold. However, the SUPPORT intervention did not strengthen any important links and failed to address several others.

Physicians' Estimates of Prognosis.—The prognostic estimates had little clinical impact. Physicians noted receiving the prognostic reports in only 59% of cases. Furthermore, the computer predictions may not have improved physicians' estimates of prognosis. On the whole, attending physicians' subjective estimates of prognosis are about as accurate as these computer projections.

Discussions Between Physicians and Patients.—The SUPPORT nurses failed to increase discussions between physicians and patients. The SUPPORT intervention did not directly address the quality of discussions by physicians.

Patients' Estimates of Prognosis.—No data are reported regarding how patients' estimates of prognosis compare with estimates by physicians or by the computer model. As mentioned, patients who overestimate their prognosis may request interventions that physicians do not consider indicated.

Physicians' Appreciation of Patients' Preferences Regarding CPR.—Reports of patient preferences from the SUPPORT intervention nurses had little effect on attending physicians. Physicians acknowledged receiving these reports in only 34% of cases. We can only speculate why the intervention was not effective, did physicians regard patients' preferences as unimportant? Did physicians believe that they already knew what patients wanted, even though studies show that physicians cannot accurately predict patients' wishes? Did physicians place little value on information communicated by the intervention nurses, compared with information they obtained firsthand?

Respect for Patients' Informed Refusals of Interventions.—About 50% of patients who wanted CPR withheld had no DNR order written. As noted, most physicians did not know patients' preferences regarding CPR. But even when physicians knew a patient's preferences, the physicians may have disregarded them as uninformed or not in the patient's best interests. No data are reported on another important issue, the preferences of the patients who died after prolonged periods in the ICU or receiving mechanical ventilation. Did these patients (or their surrogates) understand their prognosis, and did they really want these aggressive interventions started or continued so long?

Physicians' Appreciation of Patients' Pain.—Assessments of the patient's pain were not provided routinely to the attending physician. Apparently no component of the SUPPORT intervention directly addressed the problem of inadequate pain control.

Where Do We Go From Here?

Readers will no doubt draw different inferences from the SUPPORT findings. I offer several suggestions for future investigations of care near the end of life.

Don't Project Our Concept of a Good Death Onto Patients.—The authors imply that it is inappropriate that 38% of deaths followed long stays in intensive care and that 46% of DNR orders were written within 2 days of death. But consider a 65-year-old woman with septic shock and respiratory failure from a urinary tract infection. She would probably agree to intubation, hoping that the underlying infection could be successfully treated. According to SUPPORT estimates, such a patient has more than a 40% likelihood of dying in the hospital but almost a 50% probability of surviving 6 months. Her prognosis might be considered guarded or poor, but it is by no means hopeless. However, 2 weeks later, after she has developed gastrointestinal bleeding and recurrent pneumonia and cannot be extubated, she might choose to withdraw ventilation. It is reasonable for such patients to agree to a therapeutic trial of intensive care and later choose to limit interventions after their condition fails to improve. When this occurs, patients die after prolonged ICU stays, and DNR orders might be written only a few days before death. Respect for patient autonomy means that physicians must allow informed patients to determine what value they place on such a chance of survival and what risks they are willing to undergo.

Gather Preliminary Data on Promising Interventions.—In this era of shrinking resources for research, a multicenter trial usually is conducted after preliminary studies suggest that the intervention will be effective. In hindsight, the SUPPORT intervention was a promising first step. It would have been prudent to carry out smaller phase II studies of the SUPPORT intervention to determine whether it affected outcomes and intermediate variables.

Quality Improvement Requires Organizational Changes—
not change physician behavior. Recommendations by consultants in the medical record are often not followed. Providing physicians information about new drugs, vaccines, and practice guidelines does not alter their practice.10

Improving the quality of care generally requires changes in the organization and culture of the hospital and the active support of hospital leaders.13 Greco and Eisenberg4 caution that physicians will oppose changes they perceive as threatening their "self-esteem, sense of competence, or autonomy." In retrospect, was it wise to expect improvements in care at the end of life without changing the organization and culture of the hospital? Such changes might include conferences on decisions near the end of life, case management meetings regarding individual patients, individual feedback to physicians on their performance, and recognition for clinicians who provide outstanding care at the end of life. To improve pain management, clinical services might hold conferences on pain management, establish a pain consultation team, or record assessments of pain on the patient's vital signs sheet.

Physicians who are local opinion leaders can catalyze colleagues to adopt new clinical practices.14 A respected senior physician might organize seminars on how to discuss prognosis with patients, elicit their concerns and preferences for care, and negotiate a mutually acceptable plan of care. A physician recognized for communication skills could offer to accompany physicians when they discuss with patients decisions about life-sustaining interventions. This "consultant" could help the attending physician address patients' concerns and correct misunderstandings. Respected physicians may have more impact on physician-patient communication than skilled nurses because some physicians may have difficulty accepting suggestions from nurses regarding life-sustaining interventions.

Constraints and Incentives May Be Needed to Reduce Inappropriate Interventions—Some readers might reject patient autonomy as a guide to decision making at the end of life, because patients and surrogates choose ineffective, expensive interventions. Alternative approaches to reduce such interventions might include developing practice guidelines for intensive care, cutting the supply of intensive care beds and specialists, and placing intensive care physicians at financial risk for the services they provide.

Constraints and incentives have merit. However, SUPPORT did not address whether truly informed patients will choose inappropriate terminal care. Physicians often did not talk with patients. Even if conversations occurred, physicians did not appreciate patient preferences for care or did not act on them. Rather than rejecting the ideal of patient autonomy, physicians and hospitals might redouble efforts to make informed consent a reality.

Improve Discussions With Patients About Decisions at the End of Life.—Regardless of any organizational changes to reduce "inappropriate" interventions, physicians need to overcome the serious communication problems that were previously discussed. Physicians will still need to explain plans for care to patients and respond to their concerns, and objections. Incentives and constraints can facilitate these discussions. Patients and surrogates believe that beneficial interventions are being withheld and insist on care that physicians regard not indicated.13,14

Currently, physicians receive little practical talking to patients about life-sustaining interventions rarely watch senior physicians hold such on and are seldom observed by experienced physicians. Direct supervision and feedback would likely improve discussions.

The SUPPORT data present a challenge to physicians. Would be simple if computers and nurses alone could care for seriously ill patients. Instead, physicians must change hospital culture and practices and our culture. These are daunting tasks, particularly at some institutions where many physicians complain that managed care is undermining professional autonomy and reducing us to pawnsonal organizations. Although our resources may be limited, we need to reaffirm our traditional role for relieving pain, responding to patients' concerns, making difficult decisions, and respecting formed choices.

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