

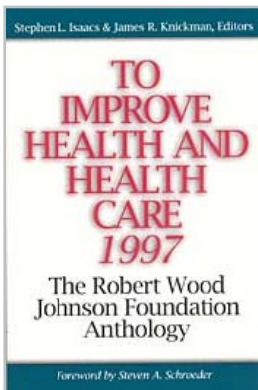
# Unexpected Returns: Insights from SUPPORT

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## *Editor's Introduction*

Chapter Eight presents selected findings and lessons from a large, multiyear research-and-demonstration project that investigated the care provided to critically ill hospitalized patients at the end of life. SUPPORT, as the study was called, was motivated by a sense that services provided to people who are dying overemphasize heroic, high-tech innovations at the expense of caring and comforting.

Although the motivation was simple, it turns out that the problem is not. This chapter describes the complexity of addressing the issue of what services ought to be delivered at the end of life and the difficulty of changing norms and practices in the world of medicine. The chapter emphasizes that it is not so simple even to identify what we mean by "the end of life."

Considerable effort was given to ensuring that the project's findings would receive widespread media attention. As a result, the project seems to be provoking the wide-ranging and, we hope, sustained debate that is necessary to make progress on this problem. The study was reported in cover stories of weekly newsmagazines and many articles in noted academic journals. The researchers have been barraged with requests to appear on television and radio shows to discuss the implications of the findings.

The findings from the demonstration project at the core of the study were negative: the interventions did not achieve the goals expected. However, the large investment by the Foundation—which has totaled approximately \$29 million to date—may have other payoffs. The findings clarified that changes in care at the end of life are not going to happen with marginal adjustments in the way we organize services. It takes a much more sustained effort on many fronts to refocus priorities for the care of the critically ill. Changes in social norms, professional values, and social priorities all need to be part of the solution.

SUPPORT suggests another lesson for a philanthropy that uses some of its resources to support research and analysis. The project was expensive in part because of the detailed, high-quality data-collection effort designed to measure outcomes associated with different interventions. This dataset is providing a range of collateral payoffs as the research team explores the data. For example, an important study published by some members of the team raises serious questions about the efficacy of the Swan-Ganz catheter, a common intervention to monitor cardiovascular function in critically

ill patients in hospitals. Thus, investments in quality datasets can lead to important research beyond the questions that motivated the data collection.

The chapter was written by Joanne Lynn, who is an Emily Davie and Joseph S. Kornfeld Foundation Scholar and the director of the Center to Improve Care of the Dying at George Washington University. Lynn codirected SUPPORT with William Knaus, who is now chairman of the Department of Health Evaluation Sciences at the University of Virginia. The insights presented emerge from the collaborations of a national team of investigators that made the project happen. Lynn was involved in the study from the beginning, and she continues to work on research and medical innovations to improve care of the critically ill. As with many of the other chapters in this book, Lynn's chapter just scratches the surface of the many findings that have emerged from this complex study. We urge interested readers to seek out some of the many articles cited in the references.

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments, or SUPPORT, collected a remarkable variety of data on 9,105 very sick hospitalized patients, identified problems in their care, and tried and failed to correct those problems. SUPPORT assembled the most comprehensive database to date describing very sick hospitalized patients and especially the care of those who die. Why the project failed to correct the problems with care remains an intriguing and enlightening focus of inquiry. This chapter provides an overview of the development and methods of the project and then examines an array of issues that SUPPORT helps to illuminate, often in unexpected ways. Some of what is reported here is straightforward, noncontroversial data; some is more speculative and challenging.

The early 1980s were marked by concerns over the cost of health care, culminating in such reforms as the use of diagnostic-related groups in the Medicare program and by highly visible controversies over patients' rights, especially at the end of life.<sup>1</sup> Fueled by a series of personal experiences that affected the leadership of the Robert Wood Johnson Foundation, a concern arose at the Foundation that elderly, fatally ill persons were likely to be vigorously treated in intensive care units, at great financial cost and suffering, even if their families objected. In 1985, the Foundation convened a meeting to consider these issues. After that meeting, the Foundation staff invited a few researchers, including William Knaus and me, to write a letter about what could be done to understand and improve care of critically ill persons in hospitals. This initiated three years of correspondence, meetings, and piloting that gradually shaped what became the SUPPORT project.

The project was carried out in two stages, with a first stage of description (1989–1991) and the second intervention (1992–1994). In planning for the first phase, the team overseeing the study at George Washington University made a number of decisions:

- Since more accurate and usable prognostication might have an important role in the treatment of critically ill patients, we decided that the study populations should be ones for which the physiology was relatively well understood. We settled on nine specific diagnoses: acute respiratory failure, multiple organ system failure with sepsis, multiple organ system failure with malignancy, chronic obstructive pulmonary disease, congestive heart failure, chronic liver failure, nontraumatic coma, colon cancer, and lung cancer.
- We determined to seek much of the important information through personal interviews. This, we decided, would be the best way to determine the functional status and cognitive ability of the patients, learn their preferences, and understand the appropriateness of intensive treatment (for example, knowing whether the patients and families understood and desperately wanted that treatment, or whether they were uninformed, confused by their options, or opposed). Proposing substantial interviews of the very sick and their families was unusual, and many observers thought it unlikely to succeed. Piloting showed, however, that patients and families were generally easy to interview, some even grateful that research was under way. As one might expect, resistance from busy physicians to intrusive and time-driven interviews was more of a problem.
- We decided to concentrate on a small number of hospitals in order to collect high-quality information intensely, but we also wanted them to be diverse and reasonably representative of national experience. In order to enroll enough patients to warrant the infrastructure, hospitals would usually have to have more than five hundred beds, and in order to be familiar with managing research and protecting subjects, they would have to be hospitals with teaching and research functions.

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The Foundation staff was closely involved throughout. One of their strong contributions was the insistence that we be committed to addressing problems the study identified; this was made a condition of participation for the eventual collaborating group. The study was perceived as being quite risky, with many more ways to fail than to succeed; funding was always for short time periods and contingent upon showing that some aspect of the study could be carried out.

In 1988, we issued a request for proposals to all American hospitals with teaching programs. The full application was completed by fifty-five hospitals; eleven were visited and five were selected.<sup>2</sup> The study was fielded in June 1989, and it enrolled patients for two years. Nearly every patient with one of the nine diseases at a defined advanced stage was enrolled.<sup>3</sup>

#### Phase I

The first phase described these serious illnesses, their outcomes, and the decision making that might shape their course. Valid, well-calibrated models to predict survival time<sup>4</sup> and serious functional disability<sup>5</sup> were major accomplishments of Phase I. We also showed that we could get high-quality data at every stage: identifying patients; interviewing patients, families, and physicians; reviewing medical records; and managing a very complex data collection and database.

By the end of Phase I, the kinds of problems that might be worth trying to improve were becoming clear.<sup>6</sup> Decision making was often far short of ideal. Physicians did not know what patients wanted with regard to resuscitation, even though these patients were at high risk of cardiac arrest. Orders against resuscitation were written in the last few days of life. Most patients who died in the hospital spent most of their last days on ventilators in intensive care. We had not expected to find the high levels of pain that were being reported, especially in noncancer illnesses. Except for the comatose, more than half of the patients with any one of the nine diseases were reported (by the patient or a family member) to have substantial pain, and we felt obliged to make reducing pain a target of the intervention.

#### Phase II

When Phase I finished enrollment, in June 1991, we faced substantial pressures to design Phase II quickly. The staff and the infrastructure at the five sites were established and effective, but costly. Some downtime allowed completion of follow-up, cleaning up records, and doing validation and reliability studies, but we could not afford to keep the teams together for long. Thus, we decided on an intervention

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by midsummer and piloted it in November. Enrollment for Phase II started in January 1992 and ran through January 1994.

The intervention included frequent reports from the computer model for prognostication and reports from interviews with patients and their families. It was anchored, however, by specially trained and committed nurses who spent all their time counseling patients and families, convening meetings with physicians and them, eliciting preferences, making plans for future contingencies, and ensuring that the best possible information about prognosis and preferences was available to the care team. These nurses managed to carry out the intervention with grace, forcefulness, and timeliness. They had some communication with all of the intervention patients' physicians; prognoses were delivered for 94 percent; patients or families met with the SUPPORT nurse in 84 percent of the cases, and, for patients who stayed at least a week in the hospital, the SUPPORT nurses averaged six visits.<sup>7</sup>

In shaping the intervention, we wanted to be absolutely sure that any benefit we claimed was really associated with the intervention itself and did not arise from changes with time or simply from the changes that people make when they are being studied. This required that there be a set of concurrent controls—people who were not receiving any intervention. Since there were substantial variations in every potential target of the study, controls would have to be established at each hospital.

We realized that it is hard to induce change, so we were willing to try a multifaceted approach. The institutions, through their institutional review boards, were concerned about the disruptive potential of the intervention. They relied on the attending physician to arbitrate whether a patient could be involved, and this decision required that we recruit all possible attending physicians. The institutions saw the proposed intervention as being like an unproved drug, and they required that reports from the prognostic models, the interviews, and the nurse's involvement be prominently labeled as research material. Thus, reports could not be given directly to the patient or the family.

In order to avoid contamination between the control and intervention patients, the patients of any one physician would either all have to have the intervention or all not have it. Since physicians were working in various collaborations, often concentrated in certain sites at the hospital, we had to allocate the intervention by physician groups. In other words, all patients of intensive care physicians at one hospital had to have the intervention, while all patients of intensive care physicians at another hospital did not.

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Otherwise, the commonplace practices of sharing patient management, rotating attending coverage, and cross-covering would lead to contamination.

Within these constraints, we tried to have the most aggressive intervention possible. We held focus groups of physicians to assess the merits of various possibilities. Those groups and a review of the literature, including the law, showed that many doctors claimed to be eager to improve care and decision making for the seriously ill, but they maintained that improvements took too much time and they often did not have the needed information about prognosis and patient preferences. We set out to reduce those time-and-information barriers.

As we geared up to initiate Phase II, we completed an ancillary study of the prevalence and outcomes of illnesses severe enough to be likely to qualify for enrollment in SUPPORT (but including people who did not come into the hospital or otherwise did not qualify), using the population around the Marshfield (Wisconsin) Clinic, one of the participating sites. This study showed that most patients with SUPPORT-like illnesses were not coming into the study, and that those who were not were disproportionately old, disabled, and cared for at home or in a nursing home.<sup>8</sup>

We also noted that our age range was lower than the national range for dying generally, and that the study actually had few patients in advanced old age. In order to capitalize on the unique opportunity offered by having an extensive data-collection arrangement in these hospitals, we added a descriptive study of the hospitalized elderly in 1994. This addition was called HELP, the Hospitalized Elderly Longitudinal Project.

The intervention phase was monitored for adverse effect by an external review committee, but otherwise data were blinded until follow-up was completed, in June 1994. During Phase II, the hospital staffs and the patients and families generally liked the intervention nurses. Two hospitals moved to continue them at the end of funding. The nurses themselves were a little skeptical that there would be an effect on the five issues chosen for formal evaluation of the effect of the intervention, though they were sure that their work was appreciated by all concerned and that it was valuable. Once the data were unblinded, it was clear that the intervention had not improved any of the five targeted problems:

1. The timing of a "do not resuscitate" (DNR) order
2. Accord between patient and physician about DNR
3. Time spent in an intensive care unit (ICU) in a coma or on a ventilator before death

4. Pain
5. Resource use<sup>9</sup>

#### INSIGHTS ABOUT DYING

Although SUPPORT was designed mainly to describe and improve outcomes and decision making regarding serious illness in hospitals, it also reported on the largest group of dying patients ever described in American hospitals. This is not a cross-section of dying; patients in SUPPORT had an established and diagnosed serious illness; they had been hospitalized and survived forty-eight hours; they were younger than the population's average age for death, and they were in large teaching hospitals. Nevertheless, describing their experience has been important. They do account for 19 percent of the adult deaths in these hospitals, but just 3 percent of the admissions.<sup>10</sup> About one-fourth of them had serious pain while they were hospitalized; the families of those who died reported that, of the half who were conscious at all in their last few days, one-half of them had moderate to severe pain most or all of the time.<sup>11</sup> Pain was spread across all diseases, not just cancer.<sup>12</sup>

While half of the SUPPORT patients died after more than one week on a ventilator in an ICU,<sup>13</sup> only 14 percent had had a resuscitation attempt when death came.<sup>14</sup> Surely that is an improvement upon the widespread utilization of cardiopulmonary resuscitation in such situations a decade or two ago, but it still is troubling. To be in SUPPORT with congestive heart failure, for example, a patient had to have too little reserve to walk around in a room, even while on maximum therapy. These are patients whose hearts are exceedingly unlikely to sustain circulation after any further injury, yet almost one-fifth of them received resuscitation at death. CPR was tried on about 5 percent of the patients with widespread lung or colon cancer.<sup>15</sup> Surely these rates would be difficult to justify.

Perhaps relatively aggressive care would be acceptable if a patient had knowingly chosen that course, but we found that there had been little discussion of such a course. When we asked patients (or their families) whether they wanted CPR, 31 percent said they would rather not have it. The physicians for the patients who preferred to avoid CPR understood that preference less than half the time. Only about one-third of the patients reported any discussion with a physician about these issues, when asked in the second week of hospitalization.<sup>16</sup> Even when patients had written advance directives, their instructions had been discussed with a physician in only 42 percent of the cases.<sup>17</sup> Effective communication between patient and physician is likely to mark some very important differences in the plan of care: we found that an

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accord on avoiding resuscitation correlated with a reduction in hospital charges for a standard patient from \$35,000 to \$21,000.<sup>18</sup>

The problem was not just that physicians were not asking patients their views. In addition, patients were not seeking to talk with physicians about such matters as resuscitation. Of those who had not talked with a physician about CPR, only 42 percent wanted to do so.<sup>19</sup> Right after we asked patients their preferences concerning CPR, we asked them whether they wanted their preferences followed or would rather have their family and physicians make decisions for them. The vast majority wanted family and doctors to make the choice. Even for those who wanted no CPR and who had no family, most wanted just their doctors to make a choice later, rather than rely upon their own choice.<sup>20</sup>

Orders to forgo resuscitation (DNR) were often written late in the hospital stays of these patients. Although 79 percent of those who died had a DNR order by the time of death, 46 percent of these orders were written in the last two days of life.<sup>21</sup> Holding aside the 14 percent of DNR orders that were written on the first day of hospitalization and might reflect plans actually made in advance, 90 percent of the discussions of DNR that were documented in the chart were followed by a DNR order, usually within a day. Only 15 percent of the DNR orders written after the first three days were written for a patient who survived this hospitalization.

In other words, DNR orders were written more as last rites for a patient expected to die rather than being considered as potentially appropriate for most of the patients most of the time. This use of DNR as a marker for expected death and as a signal to change the goals of care toward symptom management and family support actually ends up working fairly well, by some measures. Unfortunately, this practice does allow for some unexpected deaths to be attended by resuscitation efforts that might well have been forgone if the possibility of a sudden death had been considered. However, the numbers are small. For most patients, a trajectory toward death was noted in time to prohibit CPR; the discussion of the issue served to give notice to the family that death was expected; and the unsettling aspects of such a discussion were avoided until death was almost certainly in store.

Only if one feels that dying should be better is the practice troubling. Not only are there some patients for whom CPR ends up being administered, but there are also many who might have wanted to be home, or to have had the chance to say good-byes, or to have been comforted for a longer time. They did not

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have the opportunity, because waiting until death is almost inevitable also means that most were not in any condition to talk or to transfer out of the hospital.

We also learned a great deal about the prognostication of survival time and function.<sup>22</sup> Building on the methods learned in APACHE II<sup>23</sup>—a classification system for the severity of disease—we fashioned a strategy for modeling that tested a large array of variables. Most prior models had predicted survival to some event, such as hospital discharge, and usually for a very discrete population, such as those with certain diseases being given certain treatment protocols. SUPPORT predicted the likelihood of surviving to each point in time into the next six months, drawing a curve of mortality for each patient. Our model uses sixteen measures of disease and physiology that are routinely available in hospital records. It explains about two-thirds of the variation in survival time, which is about the same as physicians' estimates. In fact, the model is improved by using the physician's estimate in addition to the sixteen physiological variables.

This model is reasonably accurate. It illuminates a number of characteristics of prognostication generally. First, prognosis for sick patients is ordinarily a deep curve, with most dying in the near future. For coma, almost 90 percent of all deaths within six months happen in the first two weeks. Even for chronic lung disease and heart failure, 50 percent of all deaths within six months are in the first month.<sup>24</sup> This is, in many ways, obvious since we identified patients precisely because they were hospitalized for being sick. Clearly they were at the greatest risk of death in the near future. However, it contrasts with the way people usually think, which is to assume either that there is some future time when dying is certain ("I have six months to live") or that the risks are constant over time, given that a patient has a fatal illness.

To many, it seems quite different to say that "the average person just like you will die in two weeks" and "persons like you have a 20 percent chance to live six months." Yet these are equivalent statements for persons with acute respiratory failure in SUPPORT.<sup>25</sup>

Even more surprising to many physicians is the degree of imprecision involved in predicting near-term death. Physicians generally think that they can tell, among hospitalized patients, who is likely to die this week, even if they know that predictions are generally not so precise. However, in SUPPORT, the median patient on the day before death had one-to-four odds of living two months. Just five days ahead of death, that median patient had a 40 percent likelihood of living two months.<sup>26</sup> While those are bad odds for betting, they are not hopeless and do not make pursuing treatment vigorously seem futile.

Almost everything else studied in SUPPORT varied substantially among the five sites, but prognostication did not. In other words, what treatments and diagnoses were employed, when patients and families had discussions of resuscitation, and whether patients went home quickly all differed from one site to another. However, none of these had an effect upon survival time. Once a patient this sick was in the hospital, the specifics of what was done did not seem to matter.

In addition, we were able to build a statistical model that predicts serious functional disability at two months. Its performance is nearly as good as the model for survival time.<sup>27</sup>

In sum, SUPPORT describes the course of a large group of persons who are dying during or after hospital care. Patients experience a great deal of vigorous medical intervention and pain, but it is not at all clear that they and their families are not agreeable to what happens. No one involved talks much—not physicians, families, or patients. Decisions are made very late in the course of the illness—a practice that risks some harm and precludes planning<sup>28</sup> but protects most patients from having to consider the issues at all and spares families from confronting mortality until doing so is unavoidable.

Surely we can do better. Pain could be much more of a focus. Decisions could be made in advance, and care plans shaped much more creatively. SUPPORT did try to make changes, and the intervention failed. Clearly, long-standing habits exist for myriad poorly understood reasons and do not yield readily to change. It may well be that change requires a much more fundamental restructuring of service supply, incentives, and rewards.

#### INSIGHTS ABOUT ENGENDERING CHANGE

SUPPORT certainly showed that it is extremely difficult to change widespread and well-integrated practices—hardly a new lesson. Nevertheless, making it easy to do things better, when physicians and others claimed that they wanted to do things better, might allow improvement. The intervention that SUPPORT started was vigorously applied and widely desired. Patients and families certainly appreciated the time with the SUPPORT nurse. Physicians were generally accepting and encouraging. But old habits turned out to be not really *that* uncomfortable, and new patterns were not really *that* much desired. Most people in such hospital settings, involved with critically ill patients, are not convinced that they are doing anything wrong. They are coping with bad situations in time-honored ways. They are comfortable with the inadequacies of present practices, even when those inadequacies are acknowledged, and they are unsettled at the prospects of new and untested patterns.

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We noted that the five SUPPORT hospitals had vastly different patterns with regard to whether patients died in the hospital.<sup>29</sup> For a standard patient, the odds of being home to die varied almost fivefold: that patient was exceedingly likely to be at home to die in one site and exceedingly likely to die in the hospital at another. Variation this extreme was interesting, especially since we knew that the practice did not yield different survival times. We checked the usual suspects—family support, age, wealth, diagnoses, and so forth—and found no substantial explanations. Even the patient's preferences had no important impact, in part because virtually all patients want to be home if they can. We then employed the national dataset for Medicare, to determine whether this variation is found in that dataset. The SUPPORT hospitals arrayed themselves nicely over the range of Medicare regions. We then tried explaining this variation in terms of its correlation with various descriptors of the care system in those regions: bed supply, hospice utilization, nursing home supply, home care. These elements explained most of the variation in where patients die. Hospital bed supply alone is a stronger explanation than all the demographic and physiologic information put together. For every extra hospital bed per thousand Medicare beneficiaries, the chances of being in one to die went up by 5 percent. For every additional \$10 per Medicare beneficiary devoted to hospices, the odds went down by almost 3 percent. These are strong effects.

The importance of these findings is not in motivating a wholesale reduction in hospital beds, though that may be warranted on other grounds. Rather, it points to the fact that what happens is what usually happens, and that patients have little opportunity, really, to shape important aspects of what happens to them. Yes, of course, a strong family with substantial resources could bring a patient home to die, even in systems that did not usually provide for that. However, patients in such systems were mostly confronted with physicians who did not follow the person at home, myriad nonstandard forms to fill out, multiple competing service providers who do not share accountability or trust, and a system most comfortable doing exactly what it was doing. On the other hand, persons in systems that usually got people home before death had physicians who followed the patients in all settings, and integrated services that used the same paperwork and people to accomplish transitions. These systems probably were comfortable living with a relative scarcity of hospital beds and had learned to use other resources routinely.

Does that mean that it is necessarily better to die at home? No, not at all. Persons without families, financial resources, and safe homes almost certainly die much more miserably at home than in hospitals. Our observation shows only that what determines whether you are likely to die in a hospital has little to do with your preferences or disease or financial and social status—but everything to do with the system of social support and health care where you happen to live. If our society decides to change the care of the

dying, it almost certainly has to learn to change important aspects of the care system and not just empower patients with advance directives or the opportunity to communicate.

These observations are underscored in our work on advance directives. In the two years after passage of the Patient Self-Determination Act in 1991, during Phase II, we tracked all written living wills and durable powers of attorney, whether or not they were included in the medical record. In short, they were ineffectual in shaping care. In fact, the current practice of advance directive use failed at every key juncture. Despite a federal law requiring inquiry about them, only a minority were ever documented in the record under usual conditions. Our intervention was successful in getting virtually all advance directives recorded. However, they still had no effect upon decision making.<sup>30</sup> DNR orders were still considered only late in the course. People with preferences for a DNR order and an advance directive were no more likely to have a physician who understood than were others. Only 12 percent of the patients had discussed the writing of an advance directive with their physician, and they had discussed its existence with their physician only 42 percent of the time. We reviewed all of the documents and found that 4,804 patients had written 688 documents, only 90 of which said anything specific about treatment, and only 22 of these spoke to whether to use life-sustaining treatment in the patient's current condition.<sup>31</sup>

Clearly, advance directives as they are now employed are not a considerable part of the solution. Nevertheless, the nation has invested substantially in this approach. It is estimated to cost American hospitals up to \$100 million to comply with the Patient Self-Determination Act.<sup>32</sup> Many voluntary public organizations, lawyers, ethicists, and professional organizations have promoted advance directives. The rates of use have increased, but their actual effectiveness seems disappointingly small. Perhaps this is because the advance directives were not enough to disrupt the strong effects of habits and usual practices. Patients who have such directives are perhaps lulled into thinking that they have done something important and have solved their personal risks of overtreatment. Yet even when a patient has such a directive, care systems are allowed to continue on their usual course, not even having to undertake effective communication about the intent of the patient in writing the directive. A cynic might say that the work to promote advance directives is proving to be a lot of "sound and fury, signifying nothing," and that the work was acceptable to doctors and hospitals precisely because the directives mean little.

Other forms of advance directives, or these forms in other populations, or improved practices of advance care planning that are not so tightly linked to legal forms might well be much more effective. We would look to build upon SUPPORT's finding that for almost all of these very sick patients there was a time at

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or just before admission to the hospital when they were capable of making plans.<sup>33</sup> Further innovation and evaluation is urgently needed in order to guide policy and practice. We now feel that medical practice should incorporate progressive and pervasive advance care planning appropriate to the patient's clinical situation, and especially aiming at planning the response to predictable serious complications.<sup>34</sup> This proposal should be implemented and evaluated, as should other appealing proposals for improvement.

#### INSIGHTS ABOUT THE POWER OF MYTHS

John F. Kennedy once said, "The great enemy of the truth is very often not the lie—deliberate, contrived, and dishonest—but the myth—persistent, persuasive, and unrealistic."<sup>35</sup> How true. Some things are so widely believed that our data were taken as confirming them, even when our conclusions were quite different. When the main findings about the intervention were released, in November 1995, headlines included these: "American Way of Dying Examined: Doctors Ignorant of Patients' Wishes, New Study Reveals"; "U.S. Hospitals' Way of Death Resists Change: Study Finds Care Depersonalized, Impervious to Patients' Wishes"; and "Dying Patients' Wishes Often Ignored: Study says Doctors, Hospitals Prolong Agony, Expense." This is not what we said and not what our press release said. We stated, correctly, that patients had preferences that were not understood by physicians, and that neither patients nor physicians were talking about them. Nevertheless, we spent a great deal of time in the ensuing days trying to talk reporters out of scapegoating physicians. They clearly wanted to write about arrogant doctors and pleading patients. Imagine our surprise when we found that the headline in the press release issued by the *Journal of the American Medical Association*, which we had not seen before, said, "Care for Dying Americans Needs Substantial Improvement, Say Researchers in Largest-Ever Study of People Near Death: Study Finds Too Many Die Alone, in Pain, and Attached to Machines." Even the public relations people for physicians seemed to point the blame at doctors.

As we worked with the press, over and over we explained that the problem was much more difficult than that doctors did not hear their patients' requests; it was that no one involved was talking about these subjects. This was clearly not as good a story, and it was often not written. What showed up was the mistaken notion that patients could not get a hearing.

Similarly, the public assumes that we are spending too much money on dying people and that such outlays should be easy to stop. I appeared on a number of call-in radio shows, and someone would invariably call in to say that she had these problems all solved for herself because she had a living will. I

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would ask what it said, and the response would be that "treatment should stop when it becomes clear that I will die." When the caller was asked to clarify her wishes about treatment, she replied that treatment would stop when the situation was "hopeless." When I asked *how* hopeless the situation would have to be, or how close death had to be, the caller would predictably become testy—saying that this would be obvious. Then the caller or the host would note that doctors were just greedy and stupid in throwing lots of treatment at conditions where it was obviously futile. Often, I think I managed to force some openness by giving the data about how uncertain death is, right up to a time near its occurrence. People seemed stunned to learn that for the average person in SUPPORT the odds of living for another two months were fifty-fifty *just a week* ahead of death. However, it was very difficult to have them translate this into a recognition that the resources spent do not seem wasted until *after* the death. Before the death, they seem more like vigorous efforts to help a struggling person pull through. Afterward, they come to seem like a waste. The public must believe that physicians are quite prescient in order to think that treatment can be withheld from only the right patients.

The notion that we might save lots of money and suffering just by banning "futile" care has been enjoying widespread currency; it was dealt a major blow by SUPPORT. We simulated the effect of a policy to ban life-sustaining medical treatment for persons who had, on their third study day, a prognosis of less than 1 percent to live for two months.<sup>36</sup> At the 1 percent level, 115 people (out of 4,301 in Phase I SUPPORT) would have had treatment stopped, saving about 10 percent of their hospital expenditures. One-third of the patients did have a ventilator withdrawn, expecting death, and 83 died within two days. Three-quarters of the potential savings would rely upon just 12 patients, most of whom were young and with good functional status, and half of whom were trying to recover from a transplant. This work makes it clear that a "rule" that barred life-sustaining treatment from being used when the chances of survival were small would have little impact and would be very hard to apply.

While SUPPORT illuminated the difficulties of finding easy solutions to costs and suffering, it also underscored the devastating impact of these serious illnesses on families. We found that one-third of families lost all or most of their savings, and that more than half had at least one major disruption in living arrangements, employment, schooling, or other plans. Families endured these serious problems despite the fact that 96 percent of SUPPORT patients had health insurance.<sup>37</sup> We have recently shown that families facing these overwhelming burdens are more likely to feel that the patient prefers comfort care rather than aggressive care.<sup>38</sup>

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SUPPORT headlines trumpeted our findings on pain and dying on ventilators, and that is important. However, SUPPORT did not really collect information on the inner life experience of patients and families. This sort of information is not part of cultural myth, research studies, or popular stories. My experience in hospice care showed me that dying people and those around them can often grow greatly in understanding, can enhance relationships, and can do important personal work in their last weeks. Yet the fact that dying can grant meaning to life—the patient's and the family's—is not part of our cultural understanding. Instead, dying is just awful. Dying better is perceived to be merely less awful.

Americans also endorse a language and a conceptualization of the course of serious disease as entailing, at some point, a "transition from cure to care," finding no comfort in middling pathways. The care plan has to be conceived as aiming at cure or accepting of death, with very little time spent in transition. This is curious. For most of the diseases we studied, there is no cure, and there has not been since the time of diagnosis. What self-deception allows us to talk of cardiac medications or respirators as curative? Furthermore, people want "caring" throughout. We certainly would rather not suffer unnecessarily, even in the context of pursuing substantial prolongations of life span. Yet the idea that Americans want many things from medicine and that their prioritization admits of many possibilities is not popular. Instead, people ritualize the mantra of "transition from cure to care."

In SUPPORT, interestingly, there were mostly periods of a "full court press" until a transition to "comfort care." Very few care plans pursued ventilators and DNR orders simultaneously, for example. Instead, the DNR followed on the incipient failure of the ICU.

Medical care actually has many goals: preventing disease and disability, rehabilitating, prolonging life, curing disease, maintaining function, explaining and predicting change, restoring control, and easing suffering, for example. Ordinarily, people want them all; but in most circumstances, not all can be achieved, and in some circumstances achieving some goals entails limiting the attainment of others. Devising a plan of care requires acknowledging which goals might be achieved and being thoughtful over time about the merits of various approaches over time.

Perhaps our eagerness to have a transition from cure to care reflects our eagerness to be "other than dying" most of the time. As long as we claim to be pursuing cure, we are to be counted among the "living"—a group I sometimes label "the temporarily immortal." Once we have to accept that there is no cure but only caring, then we must acknowledge our impending mortality, and we join the "dying."

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While it is an acceptable cultural compromise for each of us to be counted among the "dying" for a period at the end of life, we want that period to be short, unavoidable, and closely tied to actual death. We do not want to be "dying" for years, or through multiple cycles of serious illness and substantial recovery. Thus, having an illusion of pursuing cure as long as the claim is not seen as silly, and of transitioning to pursuing "care" when death is close upon us, may be a way to keep from having to deal with death most of our lives. The American culture finds that appealing.

The timing of DNR orders in SUPPORT shows the effect of such a structuring of reality. Most were written as prognoses for survival dropped and within a few days of actual death. Mostly, there had not been explicit discussions with patients or families about how to plan for the likelihood of death until this discussion was undertaken. Until then, patients and families "knew" that the illness was serious, but they still thought they could beat the odds. One patient told us, "My doctor says I have 20 percent chance to live six months, but I know that I will be in that 20 percent." Another husband told his wife, "That's 25 percent, honey, that's just one of these four fingers, grab it, grab it." They were generally so optimistic about their prospects that those who acknowledged having a prognosis of 90 percent or less to live two months were dramatically more likely to prefer DNR orders and to want to talk with physicians about plans.<sup>39</sup> It was as if one could talk about rescue only until it was out of reach. Then one could talk about dying, but at that point it was often too late to change the care plan much.

The way we structure our experience—the framing we impose and the language we use—delimits what is possible. If we strongly believe, wrongly, that it is just the blindness and deafness of physicians that gets in the way of good care, we mistakenly intervene in their education and practice rather than addressing our shared responsibilities. If we structure the course of fatal illness to have a long period of pursuit of cure, followed by a short period of dying, we fail to seek out the full possibilities for worthy living throughout the course. SUPPORT's intervention may well have failed to have an effect in large part because it accepted the conventional cultural understandings rather than challenging or changing them.

#### INSIGHTS ON DECISION MAKING

Public language describes virtually all history in terms of choices and decisions. We say that "it was decided to use a ventilator," or "My doctor chose to put me in the hospital because I was breathing so hard." In medical ethics and law, virtually all actions are spoken of as decisions, and statements of optimum care systems focus heavily on optimum decision making. In a trivial sense, of course, such

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language is not inaccurate. For almost any action, another action was possible, and could have been "chosen." It is not at all clear, however, that the putative decision maker sees the options in this way.

An artist puts a daub of orange paint on a canvas in a certain way. We would not usually say he had "chosen" to paint that way. We would probably focus upon his overall vision and intent. He created that sunset with certain methods and paints. It is satisfying or not, in various ways, and we can critique his method, his vision, or his result. However, we are not likely to do so in terms of his "decisions." In much the same way, creating a life may seem more like painting, and less like a decision tree, than we usually acknowledge. We follow some pathways because they are well-trod, or because they appeal to our sense of who we are, or for emotional reasons, rather than their being justified by having the highest expected yield of benefit compared with other possibilities. We may never actually have held the other possibilities in mind.

Furthermore, what often really shapes the patient's experience might well not have been a real decision at all. Consider how often patients and families say, quite naturally, "The doctor decided that Mary needed to go to the hospital." For a person who may be dying, that is one of the most significant decisions to be made, yet it is not common in many settings for it to be posed to anyone. On the other hand, decisions about resuscitation are posed for virtually all patients, yet they actually make little difference. The patient for whom we are willing to weigh the merits of resuscitation is almost certain to be sick enough not to survive a resuscitation attempt. Furthermore, these issues will keep being raised until the care team gets permission for a DNR order, so the family that "decides" to have CPR today is likely to be convinced to see things differently tomorrow. Such a "choice" reflects a frail sense of self-determination.

SUPPORT patients and families often seemed adrift, confused, and in need of guidance about what was happening and how to respond to it. Intervention nurses spent a great deal of time explaining how a hospital works, the nature of the illness, and the resources available to help. Often, patients or family members would claim that he or she "needs to know what to do now." In a conceptual framework that assumes that decisions are what counts, they would have been understood to be seeking well-constructed decision trees and ways to elicit preferences. Taken at their word, however, they may really have simply been seeking "a way to proceed." Especially since their "choice" will be ratified by their physician, patients and families may well want "a way to proceed" more than they want to have spent a lot of effort and anxiety in seeking for a "slightly better way to proceed." When one makes choices, one bears the responsibility for them. One way to avoid some of the regret that follows when things don't work out

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well is to be sure that the course taken is "what most people would do," which may well be what was being sought in asking "how to proceed."

If these notions are true, then it is curious that we express ourselves in terms of decisions and decision making. What would be the alternative? We could simply say that thus and so was what happened, but then we sound so irrelevant. We could say that we followed the usual pathway for such situations, but that is no more satisfying. In short, we seem to like the illusion of being in control. Furthermore, as mentioned above, the discussion of DNR might signal a more important transition to acknowledging the likely immanence of death, so some of our "decisions" may function as important rituals rather than as real choices.

In any case, with whatever language, if "decisions" for the very sick merely reflect patterned behavior more often than they reflect what the patient and the family want, then reform need not start with improved information and the enabling of better decisions. It might be much better to reshape the incentives that create and sustain the patterns. In other words, reform could start with a reduction in the number of hospital beds and an increase in home care, or valuing physicians' skills in pain control or communication rather than in adjusting cardiac output.

#### INSIGHTS ABOUT THE MERITS OF MEDICAL INTERVENTIONS

SUPPORT thus far has done three evaluations of the merits of medical interventions in this population, and all three give less-than-robust encouragement to the enthusiasts of medical treatment. First, we assessed the population rate of SUPPORT-like illnesses in the Marshfield, Wisconsin area.<sup>40</sup> Some had thought that it would be uncommon to survive very long without vigorous treatment for such serious illnesses. Instead, we found that, for respiratory failure, more than half of the patients with illness severe enough to qualify were not coming into the study. Those not enrolled were generally older persons, often disabled with chronic disease, and often in nursing homes. Some never came to the hospital, and some who did were treated in regular wards, not in the intensive care unit. Whereas one-third of those who received ICU care and were enrolled in SUPPORT did die, two-thirds of those not enrolled died. Their worse baseline status undoubtedly explains some of that, and surely there is some merit to the vigorous treatment that pulled others through in intensive care. However, this comparison shows that it is not the case that all who do not get that care die. It is an error of hubris to claim that forgoing intubation, ventilation, close monitoring, and aggressive care is tantamount to certain death.

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The doubt about therapeutic optimism that arises here is buttressed by the observation that substantial site variations in all measured aspects of practice were not reflected in differences in survival time. This makes it likely that one could theoretically reduce each intervention, including communication, to the lowest level found at any site and not affect survival time overall. It is an interesting and humbling possibility.

The most striking finding in SUPPORT to date concerning the merits of our usual interventions is a study of the effects of right heart catheterization.<sup>41</sup> We had a large number of patients (5,735) who had conditions sometimes managed with right heart catheterization—a procedure that involves placing a special intravenous line into the heart and measuring pressures there. We were able to develop a scoring system that predicted the likelihood of having a right heart cath. Within each 10 percent of likelihood, some had the procedure and some did not. If right heart catheterization were a benefit, then those who got it should do somewhat better than expected in terms of survival, and those who did not should do somewhat less well. That was not what happened. In every stratum, having a cath was associated with slightly *less* good survival. In fact, in each disease type and site, the same association holds. In other words, there was no population for whom the procedure seemed to confer a benefit.

Of course, our findings will have to be confirmed elsewhere, and there are shortcomings to our study design, but the doubt these data raise should be powerful in motivating valid assessments of the merits of continuing to use right heart cath in these sick patients. It is done about 1.7 million times each year, at a direct cost of about \$2,000 each time and carrying associated costs of more than \$8,000, for a total of \$17 billion a year.

If the effect of right heart cath is harmful in this way, only a study this large and complex could show it. Not only is this finding important for its call to study the merits of this particular widely used procedure, but it is also important for illuminating an approach to evaluating a number of other procedures that have not been well assessed before being put into widespread use.

#### CONCLUSIONS

SUPPORT was a remarkable undertaking, achieved by the collaborative efforts of hundreds of people who were bound together by caring to learn how to improve the experience of seriously ill people. Data quality was high, interviewees felt well treated, and the institutions were most cooperative.

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SUPPORT is teaching us a great deal. Some of what we learned was expected. We learned to make better prognostic models, predict function as well as survival time, and describe outcomes and decision-making practices.

SUPPORT also turned out to be the largest study of dying ever done in America. The insights about how we approach dying and what patients and families experience will undoubtedly serve to anchor understanding for some time.

SUPPORT also is yielding some unexpected insights: the nature of change and agents of change, the role of decisions, the merits of treatments. It is a first look at an important field. There is much to learn before we fully understand serious illness and death and how to serve people facing them.

## Notes

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<sup>2</sup> D. J. Murphy and L. E. Cluff, "Introduction: The SUPPORT Study," *J Clin Epidemiol* 43 Suppl. (1990), v–viii; J. Lynn, J. Johnson, and R. J. Levine, "The Ethical Conduct of Health Services Research: A Case Study of 55 Institutions' Applications to the SUPPORT Project," *Clin Res* 42 (1994), 3–10.

The ICU Research Unit at the George Washington University Medical Center was the National Coordinating Center (NCC) for this study, codirected by William Knaus and Joanne Lynn. Lynn was at the Center for the Evaluative Clinical Sciences at Dartmouth College for 1992–1995 and then director of the Center to Improve Care of the Dying at the George Washington University. Knaus moved to chair the new Department of Health Evaluation Sciences at the University of Virginia in 1995. The five hospitals and their lead investigators were (1) Beth Israel Hospital in Boston, Lee Goldman (now at University of California at San Francisco) and Russell S. Phillips; (2) Cleveland MetroHealth Medical Center, Alfred F. Connors, Jr., and Neal V. Dawson; (3) Duke University Medical Center, William J. Fulkerson; (4) Marshfield Medical Research Foundation, Norman A. Desbiens, Peter Layde (now at the Medical College of Wisconsin) and Steven Broste; and (5) UCLA School of Medicine, Robert K. Oye and Neil Wenger. Frank Harrell (now at the University of Virginia) led the study's national Statistical Center at Duke University. Marilyn Bergner (deceased) and Albert Wu from The Johns Hopkins University were involved in the National Coordinating Center. The study depended upon the contributions of dozens of additional investigators, study supervisors, record abstractors, interviewers, intervention nurses, and data managers.

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<sup>6</sup> 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* 274 (1995), 1591–1598.

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<sup>11</sup> SUPPORT Principal Investigators (1995).

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<sup>16</sup> SUPPORT Principal Investigators (1995).

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