

Invitation to the Dance

Lessons from Susan Sontag's Death

by ROBERT A. BURT

The standard model for end-of-life decision-making gives roles to two parties—the physician, who explains the medical options, and the patient, who selects from among those options. The model can be harmful not only for individuals but also for the state, if the patient's right to control her own choices is understood as a positive right of access to whatever is available.

Susan Sontag's death was difficult: difficult for her because she fought it to a bitter end in a treatment regime that inflicted considerable physical and mental suffering on her, and difficult, too, for her son, David Reiff, as he testified in a sober and affecting memoir of his mother's death.¹ By Reiff's account, he was agonized by his inability or his refusal (he was never sure how to characterize his failure) to tell his mother the truth about his own evaluation of her grim prognosis, the utter futility of her desperate medical treatments at the end, and the burdens inflicted by those treatments on her and on him.

In his memoir, Reiff powerfully described the suffering that his mother endured as a result of her last

nine months of treatment for myelodysplastic syndrome, an especially lethal form of blood cancer. In the aftermath of a bone marrow transplant, "her muscles soon [became] so flaccid and wasted that she was unable even to roll over unaided, her flesh increasingly ulcerated, and her mouth so cankered that she was often unable to swallow and sometimes unable even to speak."² When the transplant failed, a powerful, unproven drug was administered to her (apparently an off-label drug approved for a different condition), but it was also unavailing. Following Sontag's death, one of her physicians wrote to Reiff, "In her final weeks, she would often complain of 'the pain all over,' and say 'I don't want any more.' However if I tried to focus on palliation, she would immediately bring the discussion back from this deep despair to when and how we could continue her therapy."³

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This distressing chronicle frames Reiff's account, but his central concern throughout the book was whether he bore any blame for his mother's suffering because he had failed to tell her his own misgivings (and even disguised from himself his true conviction) that her final treatment regime was bound to fail. If he had admitted this before she embarked on her last desperate course, he would have deprived her of hope—"that poisoned chalice of hope," as he put it, which he "endlessly refilled."⁴ And if he had admitted his persistent doubts after these treatments had failed, "it would have meant saying to her, in effect, 'your sufferings are for nothing; you gambled everything . . . but you've lost.'"⁵

Reiff tried to avert self-blame by shifting the responsibility for his mother's treatment decisions away from himself. "She was clear about what she wanted and to the extent that I am consolable about the role I played, this is what consoles me: She was entitled to her own death."⁶ At other times, he relied on her physicians and their expertise. "Yes, her chances of survival were small. But I remember thinking at the time that I simply did not have the right to be more pessimistic about her chances than her doctors were. And they were going ahead with the treatment, presumably in the belief that it was not futile, and that she was not wrong to hope."⁷

But Reiff never truly accepted these maneuvers. His memoir is suffused with ambivalence: whenever he seems to grab hold of some reason for concluding that he had behaved properly, he quickly loses his grip and slips back into self-recrimination, swimming again in that sea of death. Whether or not he had been truthful with his mother, Reiff clearly struggled to be truthful with himself in the wake of her death.

The two self-exonerating claims Reiff put forward—that responsibility for treatment decisions rested on his mother's physicians because of their expertise and on his mother, the pa-

tient, who had the clear right to choose—are at the core of our contemporary social account about medical treatment generally and the dispensation of death specifically. Reiff's account of Susan Sontag's death raises questions about the adequacy of the dyadic model of decision-making focused narrowly on individual physicians and individual patients, the

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physicians cloaked in the trappings of scientific expertise and the patients armed with their rights. This essay will explore the claims of others to participate in this decision—the claims of family members, as suggested by Reiff's account of his participation; and then the claims of third-party strangers to the patient and her physicians, such as government agencies or professional associations.

The Participatory Claims of Family

David Reiff clearly wanted to believe that the entitlement to participate in medical decision-making belonged exclusively to his mother and her physicians. But Reiff was un-

able to acquit himself of responsibility by relying on the conventional account of physicians' responsibilities and patients' rights. This inability arose because that account is, at its core, not entirely believable. Reiff's painful recounting of his struggle reveals the hidden fault lines in the contemporary account and points us toward the possibility of some reparative rethinking.

The core problem in the conventional account revealed by Susan Sontag's dying is that her physicians suppressed their doubts about the efficacy of her last-ditch treatments because they believed she wanted to exhaust every therapeutic option, no matter how remote its possibility of success or how terribly she suffered in the course of the treatment. Her physicians' unwillingness to forcefully express their doubts in turn reinforced Sontag's willingness to try even the most desperate therapeutic possibility. Her son's account portrays this elaborate shell-game of shifting responsibility that occurred between his mother and her physicians:

On one level, the calming, and sometimes even the emboldening effect of what her doctors would tell her seemed almost entirely irrational since she was hardly being told that her chances were very good. To the contrary, when pressed Stephen Nimer [Sontag's attending physician at Memorial Sloan-Kettering Cancer Center in New York] would be very frank with my mother about just how terrible her [blood cancer] was. It is true that he never allowed himself to be drawn out on whether he personally thought my mother would survive or not (though she repeatedly tried to get him to do so, and asked me to ask him on a number of occasions as well). Instead, he would reframe the question, and in doing so, or so it seemed to me, let the hope back in. My mother would almost always take a deep breath, shake her head, hair flying, and ask questions concerning the next step Nimer

wanted to take in her treatment. They would go on from there, with my mother growing visibly calmer with the passing minutes.

To be sure, the successful dynamic between them depended to a large extent on my mother not digging in her heels and simply repeating the question about whether Stephen Nimer thought she would survive or not until he was forced to reply to her either by his words or by his silence. But she never did anything of the sort, nor did she ever inquire of me whether I had in fact posed the question to Nimer myself as she had asked or how he had responded.

Of course she did not want to know the answer. . . . But it was more than my mother's fear or instinct for psychic self-preservation that determined the trajectory that these consultations with Stephen Nimer would follow. For in large measure, I always felt, it was Nimer himself who determined this outcome. Somehow, . . . Stephen Nimer managed to make the question "unaskable" on some deep level.⁸

This was not, however, Dr. Nimer's view of his interactions with Sontag. Reiff asked him, after his mother's death, "Had he taken his lead from her? Stephen Nimer did not answer directly. 'She was not ready to die,' he said. 'As far as seeking treatment, I knew from the first time I met her that she would rather die trying. There was also the feeling of loss of control and of wanting to regain control. And I did think that there were things to do for Susan. . . . Susan told me from the outset that she wanted me to do everything she could to save her life, and so we could go straight into a discussion about what she wanted and what the plan would be.'⁹

For a moment in his retrospective narrative, Reiff stepped away from describing his involvement with his

mother and her physicians to recount the views of another physician—Diane Meier, a palliative care specialist at Mount Sinai Hospital in New York—whom he consulted after his mother's death and who had not been involved in her treatment.

[Meier] spoke of "the denial, the kind of winking that goes on, where, yeah, we all know the patient's going to die but we're all going to pretend like there's hope, so we're all going to go through these rituals because that's what we believe that the patient wants. In the meantime the patient is watching the doctor, who is offering this treatment, and clearly thinking to himself, if the doctor didn't think it would work he or she wouldn't offer it, but what the doctor's not saying is that the odds are minute and that he is trying to be responsive to the needs of the patient for hope. It's like a minuet. It's surreal."¹⁰

The consequence of the minuet that Meier described is that no one can tell who is acceding to whose wishes or who wants what from whom. The participants seem to play their parts as prescribed by the dance protocol, by the conventional account that the physicians offer advice about potential benefits and risks and the patient exercises her right to choose the course of treatment. But observing from the sidelines, it is impossible to see who is leading whom; for the immediate participants, this question dissolves as they deferentially bow and curtsy toward one another.

A further consequence of this minuet is that others—Sontag's son, in this case—somehow can be excluded from the action or rendered mute notwithstanding their vast personal stakes in the outcome. This extrusion—or permission to withdraw—can, of course, be welcomed as a self-protective maneuver. But this dance move is also encouraged, even scripted, by the conventional account. As Reiff observed, he had no "right" to challenge the physicians because they

were the experts, and he had no "right" to challenge his mother because she was the patient. In the absence of any "rights" of his own, as he understood the transaction, Reiff saw himself entitled to say nothing even though he was confronted by his mother's persistent demand that he must say something. Reiff could never figure out whether he should speak honestly to his mother about his own judgment of the worth of her iatrogenic suffering or whether he was obliged to swallow his doubts and lie to her when she appeared to demand some firm assurances from him.

To respond to this bind, Reiff effectively absented himself—or, in his phrase, became "something of a stranger" to himself.¹¹ "The truth is," he said, "that I was afraid to feel anything, not least because I was so acutely aware of what my mother wanted from me—to believe that she would once more overcome the odds and recover from her disease. To do that, I had to not think."¹² The saddest aspect of this "numbing," as Reiff terms it—this depersonalization of his interactions with his mother—was the emotional distance that it bred between them as she moved irrevocably toward death. Near the end of his book, Reiff observed that his mother "who feared isolation and had the most terrible difficulties connecting with people had the loneliest of deaths. It is on that account, and that account alone, that I find myself wondering whether the false hope those close to her strived so hard to provide her with in the end consoled her or just increased that isolation."¹³

It may be that Susan Sontag's death was more difficult than most. It may be that other gravely ill people, their immediate families, and their physicians are able to negotiate this balance between hope and truth in more satisfying ways. Sontag was never prepared to decline further treatment, no matter how improbable its success or terrible its imposition of suffering. This is not the case for every irrevocably dying person. It thus may be tempting to conclude

that Sontag's death and the legacy of guilt afflicting her son for his agonized part in it is an "outlier" case that does not impeach the soundness of our contemporary institutional arrangements.

I believe, however, that there is a systemic lesson that should be drawn from Sontag's death notwithstanding its possible atypicality—a warning lesson about harmful consequences for dying patients and their families that might follow from the contemporary uncritical embrace of the rights vocabulary that shaped David Rieff's understanding of his obligations to his mother and his renunciation of any obligations to himself. The lesson is not, moreover, only applicable to the relationship of patients and their families. The dominant vocabulary of rights similarly structures relations between physicians and their patients in ways that can also inflict injury on both. The lesson I would draw is not that the vocabulary should be discarded or that patients wishes should be subordinated to the independent judgment of their families or their physicians. The lesson is that the vocabulary should be used with careful attention to the harms to patients themselves—as well as their family members and physicians—that can accrue from its rote application.

There is no formal rule about family participation that can easily be drawn from this lesson. I would not argue that family members should have a right to impose or to veto treatment decisions for the patient. It might seem tempting to give formal recognition to family participation in decision-making—for example, by providing an exception to the current confidentiality rule, so that family members are entitled to obtain the same information that the patient herself receives from her physician. But this rule, if rigidly prescribed, would not always clearly work to the advantage of patients or their immediate families (even if it were possible to draft a workable statutory definition of the entitled family members). Family participation should be under-

stood as psychologically and morally desirable but not as a legal entitlement—as a goal that should be urged though not forced on both the dying patient and her family. As David Rieff's account demonstrates, however, the contemporary framework appears to exclude family members from any recognized stake in the event; the current "rights" vocabulary

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serves to delegitimize and marginalize everyone except the dying patient and her physician. The current vocabulary tells Rieff not only that ultimate authority rests with his mother in making treatment decisions but, wrongfully, that he is not morally entitled to maintain and express his own independent judgment about her decisions.

The Participatory Claims of Strangers

The "rights" vocabulary has recently, though unsuccessfully, been invoked to exclude governmental regulators from participation in decision-making by terminally ill patients and their physicians. In a lawsuit against the Food and Drug Adminis-

tration, the Abigail Alliance for Better Access to Developmental Drugs asserted that terminally ill individuals who had exhausted all conventional remedies had a constitutional right to access experimental drugs that had not been approved by the FDA.¹⁴ Overturning a prior ruling by a three-judge panel of the court, the U.S. Court of Appeals for the District of Columbia Circuit rejected this claim. This rejection finds strong support in Rieff's depiction of the vulnerabilities of the patient-physician dyad in making bedside decisions in the context of terminal illness.

By statute, the FDA is required to screen all new drugs and "medical devices" to assure both their safety and efficacy before they could be made available for general medical use. The Abigail Alliance specifically demanded access to drugs that had passed only phase I of the FDA's required screening. Phase I tests safety for human use only in an exceedingly sketchy, preliminary way, in trials typically involving fewer than ten subjects. If no obvious danger appears in the phase I trial, then the drug testing proceeds to phase II, which involves more subjects (though usually no more than one hundred) and generates data about both safety and efficacy. If phase II demonstrates sufficient plausibility on all scores, then the research effort moves to a third phase, involving a considerably larger patient population. Only at the end of phase III do the FDA experts decide whether the drug is safe enough and efficacious enough to be offered by physicians to patients.

The FDA provides limited exceptions to this lock-step process. Under pressure from activists in the early 1990s, the FDA approved a "fast track" for earlier access to apparently promising drugs to treat AIDS; and, more generally, the FDA authorizes "compassionate use" exceptions to circumvent its ordinary processes for specific patients who have urgent need and can make a plausible, even though not entirely proven, case for the utility of drugs still under investi-

gation. These bureaucratically administered exceptions did not, however, satisfy the *Abigail Alliance* plaintiffs. They claimed that a terminally ill patient had the right to reach her own judgment about the balance of possible benefits and possible risks and that the government violated that right by denying access to any drug whose safety had been minimally verified by phase I tests. (It is not clear, as a matter of principle, why the *Abigail Alliance* plaintiffs accepted the FDA barrier for drugs that had not cleared phase I tests; perhaps, since phase I involves minimal limitations, the concession was a tactical demonstration of the plaintiffs' willingness to accept "reasonable" regulatory barriers.)

The basic premise of the FDA's elaborate, time-consuming, and expensive set of hurdles before a new drug or medical device can be approved for general use is that the scientific practice of medicine is impossible without an empirically proven evidentiary base. Physicians, so the premise goes, cannot make informed use of drugs or devices, and patients cannot give informed consent to those uses, unless reliably gathered information about safety and efficacy is available to them.

There are two related bases of resistance to demands for rigorous empirical demonstration of medical therapies (whether for drugs and medical devices subject to FDA approval or more generally envisioned—though not statutorily required—by the new intraprofessional demands for "evidence-based medicine"). First, skepticism about the need for rigorous empirical demonstration arises from within the medical profession itself based on the proposition that, aside from the difficulties of designing adequate empirical trials of safety and efficacy for all possible medical therapies, even the most rigorous demonstrations yield only statistical probabilities. Individual biological variations among patients are indeed so pronounced that there can be no proof that a given

therapy will work for or inflict harm on this particular patient. Statistical demonstrations yield only variously shaped curves, and there is no reliable way to determine where on the statistical curve a particular patient might fall. (One of the most alluring promises of new advances in genetic understanding is for more precisely tailored individual knowledge about the risks and benefits of specific therapies.)

The second ground for resisting exclusive reliance on statistical probabilities arises from a moral norm about the unique worth of every individual and the consequent right of every individual to judge that worth for herself, rather than submitting to a collectively based judgment administered by some communal agency. The scientific premise insisting on the biological uniqueness of every individual has strong connections with this normative claim. In one sense, the biological premise provides a scientific basis for confirmation of the moral premise. In another sense, the moral premise provides the passionate undercurrent for the resistance to the utter dominance of "evidence-based medicine" among some physicians and patients alike. From both perspectives, the resonant claim emerges that each person's life is unique and special and should not be viewed simply or even primarily as a member of a communal collectivity.

Shortly after David Reiff published his memoir, he wrote an article for the *New York Times Magazine* explaining the justification offered by his mother's physicians for disregarding the grim statistics against her prospects for survival. Perhaps because he was writing for a general reading public, Reiff may have overstated or oversimplified what the physicians had said to him; but what Reiff reported, or believed that he had heard, reveals the connection between the resistance to "evidence-based medicine" and the claim of an individual right to control one's own medical treatment that was put for-

ward by the plaintiffs in the *Abigail Alliance* case. Reiff stated,

What my mother wanted—which was to undergo any treatment, no matter how terrible, that promised a cure for her disease—would probably have been viewed skeptically by a physician schooled in what [Dr. Jerome] Groopman calls the "bean counting" of evidence-based medicine. But doctors like Nimer and Groopman hold that their mission is to try to treat their patients as their patients want to be treated until doing so can be called with assurance (rather than in terms of medical probability) medically futile.¹⁵

There is an unacknowledged contradiction in this position. If "assurance" regarding the prospects for cure is not based on "medical probability"—is based on something other than statistical "bean counting," in Groopman's dismissive phrase—then there is never a basis for acknowledging medical futility, never a moment when the premise of individual uniqueness and its implication that *this* patient might fall at the extreme end of the statistically rendered probability curve can be overridden. Nothing, that is, can be "called with assurance (rather than in terms of medical probability) medically futile."

The underlying implication of this position is that physicians should give unlimited deference to the patient's wishes regardless of the statistically demonstrated likelihood of therapeutic success. There might be nothing wrong with the application of this premise—indeed, it might be a basis for celebration as physician's respect for thoroughgoing patient self-determination—except for one problem. The problem is not the waste of social resources in providing treatments that lack any empirically demonstrable chance of success, unless our norms permit a physician to engage in bedside rationing that sacrifices the interests of her individual patient to the need for preserving communal resources. Some argue that we should

indeed embrace this norm in light of the extraordinary social costs involved in medical care; but the position remains controversial, at the least. The uncontroversial problem with the provision of empirically unproven treatments is rather that the individual patient's welfare might too easily be overridden—indeed, that his right to make a fully informed decision about treatment might be compromised—if his physician is willing to deploy any treatment solely because the patient requests it. The patient, that is, might too readily discount the iatrogenic suffering imposed by the treatment merely because the physician expresses willingness to go forward.

Rieff's account of his mother's experience illustrates the core dimension of this problem. He knew his mother's chances were small, yet he also thought that if her doctors were still making treatment recommendations, then they must think she had some reason to be hopeful, and he felt he had to give way before them.

Obviously, I knew that not all the doctors shared this view. My mother had started out with Dr. A., after all, and he certainly gave her no reason to believe that there was much that could be done. But Stephen Nimer at Memorial Sloan-Kettering and Jerome Groopman did not seem to believe that there was no sense in her fighting even if she wanted to. Who was I to insist that my dread was more relevant than their expertise?¹⁶

The problem with this account, however, is that it was not clear to Nimer and Groopman that they were relying on their expertise rather than on their understanding of what Sontag wanted. "Always assuming [the treatment] is not medically futile," Nimer told [Reiff] at some point during [his] mother's last weeks, "if I can carry out my patient's wishes, I want to do that."¹⁷ But the conception of "medical futility" that Nimer apparently applied was a null set; it had no em-

pirical basis and could not be falsified by any empirical data.

The physicians' professional role quintessentially involves making predictions about the expected course of patients' illnesses and the likely impact of therapeutic interventions on that illness. Patients may demand pre-

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dictive certainty, but physicians can only offer probabilities insofar as they remain true to their professional calling. Diane Meier, the palliative care physician whom Reiff consulted after his mother's death, identified this tension: "As a physician, you don't want to impose your quantitative, Cartesian view of probabilities on an individual person who says, 'That's probabilities, that's not me. I'm a fighter.'"¹⁸ The problem is, however, that a

physician cannot step outside of her statistical conception of probabilities. Predictive certainty is the province of magicians or priests. The interaction among Reiff, his mother, and her physicians became hopelessly confused when the physicians appeared to endorse Sontag's wish to "beat the odds" and thereby stepped outside their professional domain without acknowledging that they were doing so.

Sontag clearly wanted a miracle cure. But the costs of pursuing that wish were catastrophic to her. As Reiff reports,

The crux of the matter was that my mother's illness and, as soon became clear, the cumulative side effects of her treatment, increasingly had stripped her both of physical dignity and mental acuity—in short, everything except her excruciating pain and her desperate hope that the course she had embarked upon would allow her to go on living. I knew that for her the physical agony she was undergoing . . . was only bearable because of this hope.¹⁹

And her hope was kindled—perhaps not created but certainly reinforced—by the willingness of her doctors, draped in their mantle of scientific expertise, to go forward with her treatment. This is the "surreal minuet" that Diane Meier identified—patient and doctor each deferring to the other's rightful authority to control treatment decisions, with neither of them clear about who was deciding what or for what reasons decisions were being made.

This minuet would become even more misleading for many more people, even emptier of discernible content, if the plaintiffs in the *Abigail Alliance* case had prevailed. In Sontag's case, at least the terrible side effects of her bone marrow transplant were well documented; there was thus an empirical basis for her to weigh the possible risks of going forward with the treatment even though her calculus of possible benefits was confounded by the confusion of roles between her

and her physicians. If the *Abigail Alliance* plaintiffs had secured access to experimental drugs that had passed only phase I trials, there would be hopeless confusion—or, more precisely, nothing but unfounded hope—on both sides of the informational equation. Unknown risks would be balanced against unknown benefits, and utterly unsupported hope driven by an unrelenting fear of death—what Reiff sadly called the “poisoned chalice of hope”—would therefore encounter no countervailing consideration.²⁰

Fear of death is so powerful in our culture, and physicians are so habituated to see themselves as fearless warriors against death, that bedside consultation between individual patients and physicians is not a favorable site for sensible decision-making in desperate cases where conventional therapies have failed.²¹ It may seem normatively attractive to conclude, as the *Abigail Alliance* plaintiffs maintained, that where the possibility of survival is at stake, individual patients rather than physicians—much less faceless bureaucrats in a federal government agency—should decide whether the possibility of harm outweighs the unlikely prospect of benefit. But as Susan Sontag’s case demonstrates, the likelihood of systematic distortion in patient decision-making with consequent self-infliction of terrible suffering driven by nothing but unsupportable hope is so great that an avowedly paternalist intervention is justified in order to protect desperate patients against their own vulnerabilities.

This is the position that Congress has taken in constructing the elaborate FDA process of empirical validation that must be successfully completed before drugs or medical devices can be prescribed by individual physicians. The U.S. Court of Appeals for the D.C. Circuit was correct in upholding this statutory scheme. As noted, however, no comparable governmental structure imposes requirements for empirical validation of medical treatments other than drugs or medical devices. As a result, indi-

vidual physicians are much freer to promote untested therapies, constrained only by the requirement of patient consent and the minimal external supervision erratically available through individual malpractice suits. Within the medical profession itself, there have been recent efforts to promote “evidence-based medical prac-

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tice.”²² But the limitations of those efforts are apparent in the extensive and inadequately explained regional variation of medical practice across the United States.²³

The harmful consequences to patient welfare from this freewheeling approach to decision-making about medical treatments were starkly illustrated by the use of bone marrow transplants for breast cancer for some fifteen years until 1999. At its early uses, private insurance carriers refused to finance the treatments because they were not empirically validated and were thus subject to the standard

policy exclusion of “experimental therapies.” Notwithstanding the absence of empirical validation, however, growing numbers of oncologists prescribed the treatment for breast cancer patients who had failed conventional therapies, and some of these desperate patients sued their insurance carriers for breach of contract. In these high-profile cases, many trial judges ruled in the same way that Susan Sontag’s physicians had acted—that is, deferring to the patients’ desperate hopes notwithstanding the absence of scientifically based empirical validation (thus overriding their own professional norms by ignoring the contractual exclusion of such unproven therapies from insurance coverage). Faced with these litigation losses and the inevitable sympathy generated by patients desperate to prolong their lives, a consortium of insurance carriers banded together to organize and fund empirical study of the safety and efficacy of the treatment for breast cancer. After considerable delay and difficulty in recruiting suitable patients, a multicenter research protocol completed in 1999 concluded that there was no demonstrable therapeutic benefit for breast cancer from the transplant procedure.²⁴ Beyond whatever social harm resulted from these wasted social resources, the thousands of patients who accepted their physicians’ unsupported recommendations during this fifteen-year period were subjected to terrible suffering based on false hope—the same harm that Susan Sontag endured from her unjustified and unsuccessful bone marrow transplant for a different form of cancer.

One might say, as David Reiff concluded regarding his mother, that these women with breast cancer had an individual right to opt for a treatment that they viewed as hopeful, notwithstanding the consequent iatrogenic suffering. But if the hope arises because of a scientific mystique surrounding the physician’s recommendation, while the physician relies on what she thinks her patient wants rather than on the empirical valida-

tion demanded by the application of scientific standards to the practice, then the stage is set for the “surreal minuet”—the passing of the “poisoned chalice of hope”—that distorted the interactions between Susan Sontag and her physicians. Bedside decision-making between individual physicians and patients is not conducive to preventing physicians from straying outside their professional competence or preventing patients from confusing their desperate wishes with their realistic prospects for medical assistance. Communally organized protections are necessary to achieve these protections—whether through direct governmental oversight or delegated authority to professional organizations.

Within the medical profession itself, there is a strong traditional impetus to defer to the decisions of individual attending physicians. Institutional processes for consultative decision-making—for example, semiformal “tumor boards” where physicians in cancer-care hospitals deliberate about treatment alternatives—have made some inroads on this traditional culture. But these consultative processes still remain essentially dependent on the willingness of attending physicians to refer their cases. Intraprofessional social pressure should underscore the practical and moral

reasons for going beyond the individual patient-physician dyad for decision-making in the same way that social pressure should be deployed to include family members in decision-making. Unlike family participation, however, a clinching case can be made for mandatory inclusion of the wider community of physicians, and ultimately of government agencies such as the FDA, in prescribing professional standards of practice.

War, it is said, is too important to be left to the military; just so, death is too confounding to be left to the isolated decisions of individual patients and their physicians. Bestowing legitimacy on a broader range of participants than the individual patient and physician might lead us toward a more inclusive moral vocabulary, and one that will help appease the terrors and ultimate incomprehensibility of death.

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