Illness as More Than Metaphor

By DAVID RIEFF

My mother, Susan Sontag, lived almost her entire 71 years believing that she was a person who would beat the odds. Even during the last nine months of her life, after she was discovered to have myelodysplastic syndrome, or M.D.S., a particularly virulent blood cancer, she continued to persevere in the belief that she would be the exception. M.D.S. is technically a precursor to acute myeloid leukemia. On average, its survival rates across the generational cohorts are no better than 20 percent, and far worse for a woman in her early 70's who had had cancer twice before. It wasn't that she didn't know that the biological deck was stacked against her; as someone who prided herself on her ability to grasp medical facts, she knew it only too well. In the immediate aftermath of her diagnosis, she went online to learn all she could about M.D.S. and despaired as the fact of its lethality sank in. But that despair was almost the flip side of a lifelong confidence in her ability to defy the odds. "This time, for the first time," she told me, "I don't feel special."

Remarkably, in only a few weeks she had righted herself psychologically and was gearing up, just as she had done during her successful fights to survive two previous cancers, to find the doctors and the treatments that seemed to offer her some hope of defying those terrifyingly long odds and once more becoming the exception. How she did this, I don't know. Perhaps it was the spirit that had led her, when she recovered from her first cancer, to write a little proudly in her book "AIDS and Its Metaphors" of "confounding my doctors' pessimism." Perhaps she was able, somehow, to confound her own as well. What I do know is that the panic attacks that had overwhelmed her after her diagnosis began to lessen, and in the M.D.S. literature that she found on the Web she began to find reasons for hope rather than despair. She even began to work again, writing a fiery piece on the Abu Ghraib torture photographs for this magazine at the same time she was readying herself to become a patient at the Fred Hutchinson Cancer Research Center in Seattle, where the bone-marrow transplant that was her only realistic hope of cure had been pioneered.

Her "positive denial," as I always thought of it, whether with regard to her health, her work as a writer or her private life, had not been extinguished by the hard facts of M.D.S. after all. On her 70th birthday, 15 months before she found out she was ill again, she talked to me at length and with the characteristic passion she brought to her work about how she was only now starting a new and, she thought, the best phase of her writing life. Leaving for Seattle, she began speaking again of projects she would undertake - above all the novel she had been outlining - after her return to New York and even to speculate about whether she would feel strong enough to write during her treatment.

Was it bravado? Doubtless it was, but not bravado alone. During the two years of chemotherapy she underwent in the mid-1970's to treat her first cancer - Stage 4 breast cancer that had spread into 31 of her lymph nodes - she managed to publish a book on photography and, a year later, her book "Illness as Metaphor." That time, she had beaten the odds. William Cahan, then her principal doctor at Memorial Sloan-Kettering Cancer Center in New York, told me at the time that he saw virtually no hope. (Those were the days when doctors often told patients' relatives things they did not disclose to the patients themselves.) But as her friend Dr. Jerome Groopman, chief of experimental medicine at the Beth Israel Deaconess Medical Center in Boston, told me a few months after her death: "The statistics only get you so far. There are always people at the tail of the curve. They survive, miraculously, like your mother with breast cancer. Her prognosis was horrific. She said: 'No, I'm too young and stubborn. I want to go for it'" - meaning
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"We tell ourselves stories in order to live." The line is Joan Didion's, and looking back on my mother's life, I've been wondering lately if we don't tell them to ourselves in order to die as well. In retrospect, I realize that death was never something my mother talked about much. But it was the ghost at the banquet of many of her conversations, expressed particularly in her single-minded focus on her own longevity and, as she got older, by her frequent voicing of the hope of living to be 100. She was no more reconciled to extinction at 71 than she had been at 42. After her death, a theme in many of the extremely generous and heartfelt letters of condolence I received from her friends puzzled me: it was surprise - surprise that my mother hadn't beaten M.D.S. as she had beaten both breast cancer and the uterine sarcoma that struck her in her mid-60's.

But then, she, too, was surprised when the doctors in Seattle came in to tell her the bone-marrow transplant had failed and her leukemia was back. She screamed out, "But this means I'm going to die!"

I will never forget that scream, or think of it without wanting to cry out myself. And yet, even that terrible morning, in a pristine room at the University of Washington Medical Center, with its incongruously beautiful view of Lake Union and Mount Rainier in the background, I remember being surprised by her surprise. I suppose I shouldn't have been. There are those who can reconcile themselves to death and those who can't. Increasingly, I've come to think that it is one of the most important ways the world divides up. Anecdotally, after all those hours I spent in doctors' outer offices and in hospital lobbies, cafeterias and family rooms, my sense is that the loved ones of desperately ill people divide the same way.

For doctors, understanding and figuring out how to respond to an individual patient's perspective - continue to fight for life when chances of survival are slim, or acquiesce and try to make the best of whatever time remains? - can be almost as grave a responsibility as the more scientific challenge of treating disease. In trying to come to terms with my mother's death, I wanted to understand the work of the oncologists who treated her and what treating her meant to them, both humanly and scientifically. What chance was there really of translating a patient's hope for survival into the reality of a cure? One common thread in what they told me was that interpreting a patient's wishes is as much art as science. Dr. Stephen Nimer, my mother's principal doctor, heads the division of hematologic oncology at Memorial Sloan-Kettering and is also one of America's foremost researchers in the fundamental biology of leukemia. As he explained it to me: "The fact is that people are never as educated as the doctor. You have to figure out something about the patient" - by which he meant something that takes both patient and physician beyond the profound, frustrating and often infantilizing asymmetry between the patient's ability to comprehend the choices to be made and the doctor's.

Still, the doctor's task here is not impossible. As Nimer put it: "There are risk takers and risk-averse. There are those who say, you know: 'I'm 70 years old. If I get another four or five months, that would be fine.' Others say, 'You do everything you can to save my life.' Then it's easy. You can go straight into a discussion of what a patient wants."

For Nimer, as for Jerome Groopman, the ethical challenge, vital for a doctor to recognize and impossible (and ethically undesirable) to deal with formulaically, comes not with the 30 percent of patients Nimer estimates know for certain whether they want aggressive treatment or not, but with the "undecided" 70 percent in the middle. As Nimer told me somewhat ruefully, the doctor's power to influence these patients, one way or the other, is virtually complete. "There are ways to say things," he said. "This is your only hope. Or you could say, 'Some doctors will say it's your only hope, but it has a 20 times better chance of harming you than helping you.' So I'm pretty confident I can persuade people." Groopman, in his clinical practice with patients like my mother, patients for whom, statistically, the prognosis is terrible, at times begins by saying,
"There is a very small chance, but it comes with tremendous cost."

In these situations, doctors like Groopman and Nimer see their job as, in effect, parsing the patient's response and trying to determine a treatment plan that is responsive to the patient's wishes but is also not what physicians refer to as "medically futile" - that is, offering no real chance for cure or remission. That is hard enough. What makes the doctor's decision in such situations even more painful is that "medically futile" means different things to different physicians. After my mother's transplant failed and she was medevacked from the University of Washington hospital back to Memorial Sloan-Kettering, Nimer tried one last treatment - an experimental drug called Zarnestra that had induced remission in some 10 percent of the small number of patients to whom it had been administered. I would learn from the nurses' aides who attended my mother in the last weeks of her life that some of the doctors and nurses on the transplant floor were uncomfortable with the decision, precisely because they saw my mother's situation as hopeless, that is, medically futile. As division head, in consultation with Dr. Marcel van den Brink, the hospital's chief of bone-marrow transplantation, Nimer could overrule these objections. But neither man would have denied the difficulty of drawing a clear line between what is and is not medically futile.

My mother was determined to try to live no matter how terrible her suffering. Her choices had been stark from the outset. Unlike some other cancers that can be halted for years through treatment, there are few long-lasting remissions in M.D.S. Her only real chance of survival lay in the possibility of an outright cure offered by an adult-blood-stem-cell transplant. Otherwise, to quote from one of the medical Web sites my mother visited repeatedly during the first weeks after her diagnosis, treatment offered her only an "alleviation of symptoms, reduction in transfusion requirements and improvement of quality of life." During their second meeting, Nimer offered her the option of treatment with a drug called 5-azacitidine, which gave many M.D.S. patients some months during which they felt relatively well. But the drug did little to prolong life. My mother replied, with tremendous passion, "I am not interested in quality of life!"

What Nimer knew with the horrorified intimacy of long clinical practice, but what my mother could not yet know, was just how agonizing the effects of an unsuccessful stem-cell transplant can be: everything from painful skin rashes to inordinately severe diarrhea to hallucinations and delirium. To me, torture is not too strong or hyperbolic a word. After my mother's declaration, Nimer only nodded and began talking about where the best place might be for her to have the stem-cell transplant, going over with her the variations in different medical research centers' approaches to transplantation. After the transplant failed, and my mother returned from Seattle, Nimer obviously knew how long the odds were against an experimental drug like Zarnestra inducing even a brief extension of her life. But he said he felt that he had to try, both because the drug had had some success and because my mother had told him (and me) from the outset that she wanted her doctors to do everything possible, no matter how much of a long shot it was, to save or prolong her life.

"Always assuming it's not medically futile," he told me a few weeks before her death, "if I can carry out my patients' wishes, I want to do that."

My mother could express herself only with the greatest of difficulty in the last weeks of her life. "Protective hibernation" was how one Sloan-Kettering psychiatrist described it. Like most people who have lost someone dear to them, I would say that one of my dominant emotions since my mother's death has been guilt - guilt over what I did and failed to do. But I do not regret trying to get her to swallow those Zarnestra pills even when her death was near, for I haven't the slightest doubt that had she been able to make her wishes known, my mother would have said she wanted to fight for her life to the very end.

But this does nothing to change the fact that it seems almost impossible to develop a satisfactory definition
of what is and is not medically futile. What is the cutoff? A 10 percent chance of success? Five percent? One percent? When does the "very small chance" my mother's doctors bought at the "tremendous cost" in suffering that Groopman described for me become so infinitesimal as to make it no longer worth trying?

I have found no consensus among the oncologists I have spoken with in the aftermath of my mother's death, and I don't believe there is one. There are those who take a strong, consistent stance against not just such treatments but also against the general orientation of American medicine, particularly oncology, toward doing everything possible to save individual patients, no matter how poor their chances. These doctors seem inspired by a public-health model based on better health outcomes for communities rather than individuals, viewing it as the most moral and the only cost-effective way of practicing medicine. This view, often associated with the work of the medical ethicist Daniel Callahan, is increasingly influential.

One reason for this is that the current American medical system is breaking down. Several physicians with little sympathy for Callahan's approach pointed out to me that, like it or not, American society either can't afford or no longer chooses to afford to underwrite the kind of heroic care people like my mother, whose prognoses are obviously poor, still receive in the United States. Dr. Diane E. Meier, a palliative-medicine specialist at Mount Sinai Hospital in New York, remarked that if we as a society spent the sort of money on medical care that we spend, say, on the military, the challenge facing physicians would be very different. But neither Meier nor any other doctor I spoke to seemed to believe that there is much chance of that. If anything, medical financing has moved and is likely to continue to move entirely in the opposite direction. As Meier put it to me, "The cost crisis facing Medicare will lead to substantial and real reductions in access to care."

One illustration of Meier's point is that Memorial Sloan-Kettering already treats, through funds received from private philanthropists, many patients whose treatment is not covered by Medicare or who have had their applications for treatment at major cancer centers refused by their insurance companies. But it is one of only a few cancer centers in a position to do so. (Even more sobering is the statistic that only a small percentage of Americans with cancer are treated in a cancer center.) Philanthropy aside - and even the most generous philanthropy can never make up the shortfall the continuing cuts in federal financing are likely to produce - it may well be, as Meier suggests, that we are rapidly moving toward a health care system in which "only the rich will be able to choose the treatment they want."

In a sense, the financial background of my mother's treatment prefigured the world Meier was describing. Once she and Nimer agreed that she would have a bone-marrow transplant at the Hutchinson Center, and she was accepted as a patient there, she applied to Medicare - her primary insurance - for coverage of the treatment. Medicare refused, saying that coverage could begin only once her M.D.S. had "converted" to full-blown leukemia; in other words, when she was far sicker. My mother then applied to her private insurance company. The response was that her coverage did not extend to organ transplants, which was what it considered a bone-marrow transplant to be. Later, my mother's insurance company relented but still refused to allow her to go "out of network" to the Hutchinson Center, even though Nimer was convinced that the doctors there stood the best chance of saving her life. Instead, the insurer proposed four "in network" options - hospitals where it would pay for the transplant to be done. But three out of the four said they would not take a patient like my mother (because of her age and medical history). The fourth did agree to take her but admitted, frankly, that it had little experience with patients of her age.

My mother was determined to get the best treatment possible, and Nimer had told her that treatment was to be found in Seattle. So she persevered. She was admitted to the Hutchinson Center as a so-called self-pay patient and had to put down a deposit of $256,000. Even before that, she had to pay $45,000 for the search for a compatible bone-marrow donor.
The knowledge that she was getting the best treatment available, both at Sloan-Kettering and at Hutchinson, was a tremendous consolation to my mother. It strengthened her will to fight, her will to live. But of course she was getting that treatment only because she had the money to pay for it. To be sure, as she was doing so, her doctors both in Seattle and New York very generously helped with her appeal of her insurance company's decision - calling and writing letters providing documentation and expert opinions explaining why the only viable treatment option was the one they had recommended. But both she and they knew that whatever hope she had of cure depended on moving rapidly toward the bone-marrow transplant. This would have been impossible had she not had the money to in effect defy her insurer's verdict, even as she was appealing it legally.

Let me state the obvious: The number of Americans who can do what she did is a tiny percentage of the population, and while I shall always be thankful beyond words for the treatment she received, and believe that she and her doctors made the right choice, I cannot honestly say that there was anything fair about it.

How or whether the realities of the health care system in America today can be reconciled with the fundamental aspiration of science, which is discovery, and the fundamental aspiration of medicine, which is to cure disease, is impossible for me to say. But if the time I have spent in the company of oncologists and researchers convinces me of anything, it is that these aspirations are almost as fundamental in serious doctors as the will to live is in cancer patients. The possibility of discovery, of research, is like a magnet. Marcel van den Brink, the Sloan-Kettering bone-marrow chief, who is Dutch, told me that one of the main reasons he is in the United States is that here, unlike in the Netherlands or, he thought, in the other major Western European countries, there is money for his research. For his part, Jerome Groopman emphasized the overwhelming number of foreign researchers in his lab. He described it as "the opposite of outsourcing - it's insourcing."

Researchers find inspiration in the example of AIDS research, an almost paradigmatic example of heroic, cost-indifferent medicine. By public-health standards, AIDS has received a big share of the nation's medical resources, in large measure thanks to the tireless campaigning of gay Americans who have had the economic clout and cultural sophistication to make their voices heard by decision-makers in the medical establishment and in government. As Dr. Fred Appelbaum, clinical-research director of the Hutchinson Center, pointed out to me, understanding AIDS and then devising treatments for it at first defied the best efforts of research scientists. And though a cure has not yet been found, effective treatments have been - albeit, extremely expensive ones.

If there is a difference between AIDS research and cancer research, it is that while advances in AIDS came relatively quickly, advances in cancer treatment and, indeed, in the fundamental understanding of how cancer works have come far more slowly than many people expected. Periodically since 1971, when President Nixon declared his war on cancer, the sense that the corner is about to be turned takes hold. We appear to be in such a moment today. The National Cancer Institute has recently put forward ambitious benchmarks for progress in cancer research and treatment. As its director, Dr. Andrew von Eschenbach, a respected surgeon and a cancer survivor himself (he is also acting head of the Food and Drug Administration), put it recently: "The caterpillar is about to turn into a butterfly. I have never known more enthusiasm among cancer researchers. It's a pivotal moment." The suffering of cancer, he argued, will be well on its way to being alleviated by 2015.

The media have mostly echoed this optimism. It is not unusual to read about the latest "breakthrough" in cancer treatment, both in terms of understanding the basic biological processes involved and with regard to innovative new drug therapies. On the level of research, there is no doubt that significant progress has been made. Dr. Harold Varmus, the Nobel laureate who now heads Memorial Sloan-Kettering, is emphatic on the
subject. "Fifty or 60 years ago," he told me, "we didn't know what genes were. Thirty or so years ago we didn't know what cancer genes were. Twenty years ago we didn't know what human cancer genes were. Ten years ago we didn't have any drugs to inhibit any of these guys. It seems to me we've made an awful lot of progress in one person's lifetime."

Other research scientists seemed far more pessimistic when I spoke with them. Dr. Lee Hartwell, also a Nobel laureate, is president and director of the Hutchinson Center. He has urged that the focus in cancer treatment shift from drug development to the new disciplines of genomics and, above all, proteomics, the study of human proteins. Though he acknowledged the profound advances in knowledge made over the past two decades, Hartwell emphasized a different question: "How well are we applying our knowledge to the problem? The therapy side of things has been a pretty weak story. There have been advances: we cure most childhood leukemias with chemotherapy, for one thing. But the progress has been surprisingly weak given the huge expenditures that we've made. We're spending over $25 billion a year improving cancer outcomes, if you include the spending of the pharmaceutical companies. So you've got to ask yourself whether this is the right approach."

The focus needs to be on "diagnostics rather than therapeutics," Hartwell said. "If you catch a cancer at Stage 1 or 2, almost everybody lives. If you catch it at Stage 3 or 4, almost everybody dies. We know from cervical cancer that by screening you can reduce cancer up to 70 percent. We're just not spending enough of our resources working to find markers for early detection."

Some researchers are even more skeptical. Mark Greene, the John Eckman professor of medical science at the University of Pennsylvania and the scientist whose lab did much of the fundamental work on Herceptin, the first important new type of drug specifically designed to target the proteins in the genes that cause cells to become malignant, agrees with Hartwell. The best way to deal with cancer, he told me, is to "treat early, because basic understanding of advanced cancer is almost nonexistent, and people with advanced cancer do little better now than they did 20 years ago."

Varmus, who appears to be somewhere in the middle between the optimists and the pessimists, told me that so far the clinical results are mixed. As he put it: "Many cancers are highly treatable. I am optimistic, but I'm not saying, 'Here's when.'"

The irreducible fact is that failure is the clinical oncologist's constant companion. Each of those who treated my mother seemed to have evolved a strategy for coping with this. Stephen Nimer said: "I'd have to be an idiot to think everything I do works. I mean, where have I been the last 20 years? I'm not afraid to fail." Fred Appelbaum put it still more plainly. "You get victories that help balance the losses," he said. "But the losses are very painful."

Appelbaum's almost studied understatement brought home a question that had recurred through the savage months of my mother's illness and also after her death. I kept wondering how the doctors who were treating her with such determination, against all the odds, could possibly stand swimming in this sea of death that they confronted every day, since they did not have the luxury of pretending, at least to themselves, that they didn't know which of their patients were likely to make it and which were not.

The question made sense to some. For Nimer, though, it did not. "I prefer 'swimming in a sea of life,'" he said, adding: "I know I'm not going to save everyone, but I don't think of myself as swimming in a sea of death. People who have congestive heart failure, their outcomes are like the worst cancers. People think of it as a cleaner death and cancer as a dirtier death, but that's not the case. I approach things with the question 'What would it be like if I were on the other side?' The first thing is being dependable. I give people..."
a way to always reach me. They're not going to call me frivolously. There's a peace of mind that comes with knowing you can reach a doctor. I think if you have one of these diseases, you know you can die. Before people get to the time of dying, people want to have some hope, some meaning, that there's a chance things can get better."

And when they don't, Nimer continued, "whatever happens is going to happen. But how about the ride? How rough will it be? If I were dying, the thing I'd worry about most is how much I'm going to suffer. I've had a lot of people die over the years. One thing is to reassure people, 'Look, I'm going to do whatever is humanly possible so that you don't suffer.' We're all going to die, but I'm going to spend just as much time paying attention to your last days as I do at the beginning."

And with my mother, that is exactly what he did in the moment of her death - one of the many, too many, Nimer has seen. With all due respect to him, if that's not swimming in a sea of death...

If my mother had imagined herself special, her last illness cruelly exposed the frailty of that conceit. It was merciless in the toll of pain and fear that it exacted. My mother, who feared extinction above all else, was in anguish over its imminence. Shortly before she died, she turned to one of the nurses' aides - a superb woman who cared for her as she would have her own mother - and said, "I'm going to die," and then began to weep. And yet, if her illness was merciless, her death was merciful. About 48 hours before the end, she began to fail, complaining of generalized low-grade pain (possibly indicating that the leukemia was in her bloodstream). Shortly after, she came down with an infection. Given the compromised state of her immune system, the doctors said, there was little chance that her body could stave it off. She remained intermittently lucid for about another day, though her throat was so abraded that she could barely speak audibly and she was confused. I feel she knew I was there, but I am not at all sure. She said she was dying. She asked if she was crazy.

By Monday afternoon, she had left us, though she was still alive. Pre-terminal, the doctors call it. It was not that she wasn't there or was unconscious. But she had gone to a place deep within herself, to some last redoubt of her being, at least as I imagine it. What she took in I will never know, but she could no longer make much contact, if, indeed, she even wanted to. I and the others who were at her side left around 11 p.m. and went home to get a few hours' sleep. At 3:30 a.m. on Tuesday, a nurse called. My mother was failing. When we arrived in her room, we found her hooked up to an oxygen machine. Her blood pressure had already dropped into a perilous zone and was dropping steadily, her pulse was weakening and the oxygen level in her blood was dropping.

For an hour and a half, my mother seemed to hold her own. Then she began the last step. At 6 a.m., I called Nimer, who came over immediately. He stayed with her throughout her death.

And her death was easy, as deaths go, in the sense that she was in little pain and little visible anguish. She simply went. First, she took a deep breath; there was a pause of 40 seconds, such an agonizing, open-ended time if you are watching a human being end; then another deep breath. This went on for no more than a few minutes. Then the pause became permanence, the person ceased to be and Nimer said, "She's gone."

A few days after my mother died, Nimer sent me an e-mail message. "I think about Susan all the time," he wrote. And then he added, "We have to do better."

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