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## The Web of Relations: Thinking About Physicians and Patients

Ellen Wright Clayton, M.D, J.D.\*

Like the other contributors to this symposium, I owe a profound debt to Jay Katz for his intellectual rigor, his gentle but firm Socratic pedagogy, and his unparalleled generosity of time and friendship. I first met Jay during my last year of law school when, at the urging of friends, I enrolled in his seminar on informed consent. By that time, he had collected most of the materials on which he based his important book. Not surprisingly, a single semester could not contain all of that material, so many of us continued on into the second semester. During that time I learned a number of things, but largely in the abstract mode that often characterizes the law school classroom. Fortunately, I had the opportunity after my first year in medical school to work on Jay's book, *The Silent World of Doctor and Patient*.<sup>1</sup> I am not sure that I contributed much. I have always viewed that summer as Jay's effort to create a tutorial designed to make sure I "got it." Even so, it required actually taking care of patients for the last twenty years to bring some of his lessons home.

Over the years, I have come to see the physician-patient relationship not simply as a dyad of autonomous individuals, but as one part, albeit an important and complex part, of a web of dynamic interactions that influence both parties. This perspective has important implications. The work of Barabási<sup>2</sup> and others<sup>3</sup> has shown that networks are fluid, self-creating, and always changing. At the same time, networks tend to respond poorly or unexpectedly to deliberate

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\* Rosalind E. Franklin Professor of Genetics and Health Policy, Professor of Pediatrics, Professor of Law, and Co-Director of the Center for Biomedical Ethics and Society, Vanderbilt University. This Article was inspired by Professor Katz, the mentor and teacher whose guidance has shaped my career in countless ways. I would like to thank Jay Clayton for his insightful comments as this project evolved.

1. JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (Johns Hopkins Univ. Press 2002) (1984).

2. See generally ALBERT-LASZLÓ BARABÁSI, *LINKED: HOW EVERYTHING IS CONNECTED TO EVERYTHING ELSE AND WHAT IT MEANS FOR BUSINESS, SCIENCE, AND EVERYDAY LIFE* (2003).

3. See, e.g., SERGEI N. DOROGOVTSSEV & JOSÉ F. F. MENDES, *EVOLUTION OF NETWORKS: FROM BIOLOGICAL NETS TO THE INTERNET AND WWW* (2003); Stephen H. Strogatz, *Exploring Complex Networks*, 410 NATURE 268, 268-76 (2001).

attempts to induce change. Pressure at one point can lead to a countervailing response at another. This understanding provides additional insights into people's actions and suggests both reasons for resistance as well as the possibility of support from unanticipated sources.

In rereading Jay's book, I was struck by its prescience and by some of the questions and dilemmas that remain unresolved or have emerged in new forms. One of the most powerful stories for me in his book is that of Iphigenia Jones, the twenty-one-year-old woman who, shortly before her wedding, discovered that she had developed breast cancer. At the suggestion of her surgeon, she initially agreed to have a mastectomy because he firmly believed it was the best alternative. He later decided to tell her about other options because of "his misgivings about having to perform such a mutilating procedure on a person that young and attractive."<sup>4</sup> After much thought, she chose lumpectomy and radiation (an approach now referred to as "breast conserving therapy" or BCT), later expressing in a public forum "her great joy over now being able to begin life with her beloved physically unscarred."<sup>5</sup> The original surgeon apparently was comfortable with her decision, but the physicians who listened to her story almost unanimously agreed that it had been crazy or inappropriate to let her choose her therapy.

Twenty years later, this story elicits an array of issues and questions, some old and some new. I, for one, feel more than a twinge of irritation every time I read that the surgeon had second thoughts about his decision (only) because she was young and pretty. It was a wonderful thing that he decided to offer her more options, but other women should have had those choices as well. The discriminatory attitudes and stereotypes that pervade society, in this case with respect to gender, not surprisingly affect the physician-patient relationship as well as the delivery of health care more generally. These effects are now the subjects of intense scrutiny, and evidence is mounting that differences in health are attributable in part to provider attitudes about what sorts of intervention are appropriate for different people.<sup>6</sup> The government has set aggressive goals for decreasing disparities in health outcomes, but they will be difficult to achieve without addressing discriminatory provider attitudes.

Happily, the notion of shared decision-making has made sufficient inroads

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4. KATZ, *supra* note 1, at 90-91.

5. *Id.* at 91.

6. For example, white men are more often offered cardiac catheterization and thrombolysis in the event of a heart attack than are minorities or women. *See generally* COMM. ON UNDERSTANDING & ELIMINATING RACIAL & ETHNIC DISPARITIES IN HEALTH CARE BD. OF HEALTH SCI. POLICY, INST. OF MED., *UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE* (Brian D. Smedley, et al. eds., 2003).

today that it would be uncommon to find a chorus of physicians who would publicly admit that it was crazy to let Iphigenia make her own choice. Many doctors probably believe that her surgeon should have made the decision or at least made her go along with his recommendation, but most would hesitate to admit to such a blatant disregard of patients' wishes. Nonetheless, a study reported in the *Journal of the American Medical Association*<sup>7</sup> in 2004 reveals some of the problems that still remain. Following up on studies demonstrating that women who had BCT had equivalent survival rates and greater quality of life and satisfaction with the procedure than those who received more aggressive surgery, the authors developed a "decision board" with information about the various options to improve patient communication. The board included explanations of treatment choices, side effects, implications for the breast, and implications for long-term survival, which were then read together by the patient and the surgeon. The researchers recruited community surgeons from Ontario, Canada, to compare consultations using a decision board with those using surgeons' normal procedures for disclosure. The authors reported that the women whose surgeons used the decision board knew more about their treatment options, were more satisfied with their decision-making, and were more likely to choose BCT. Put another way, usual practice still is not good enough to empower women to make decisions that fit their lives. These findings are all the more striking because the surgeons who agreed to participate in this trial were probably more likely than most physicians to believe in the importance of exploring options. It is difficult to imagine, for example, that a physician who believed that mastectomy was the only appropriate intervention would have agreed to take part in this research.

Iphigenia's case might proceed differently today. Many women diagnosed with breast cancer at the age of twenty-one are offered genetic counseling. Particularly if other members of her family had also been affected, she might be offered genetic testing. Happily, in the absence of a positive family history, her risk of having a germline mutation that would have predisposed her to develop cancer would be less than fifteen percent despite her youth.<sup>8</sup> But if she decided to proceed with testing that uncovered a harmful mutation, her decision about surgery could well have been different. Several investigators have shown that women with breast cancer who are found to have these mutations before the time

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7. Timothy Whelan et al., *Effect of a Decision Aid on Knowledge and Treatment Decision Making for Breast Cancer Surgery: A Randomized Trial*, 292 JAMA 435 (2004).

8. See Kathleen E. Malone et al., *BRCA1 Mutations and Breast Cancer in the General Population: Analyses in Women Before Age 35 Years and in Women Before Age 45 Years with First-Degree Family History*, 279 JAMA 922 (1998); Beth Newman et al., *Frequency of Breast Cancer Attributable to BRCA1 in a Population-Based Series of American Women*, 279 JAMA 915 (1998).

of surgery are more likely to choose bilateral mastectomy.<sup>9</sup> Some of their choices may reflect the growing consensus that more aggressive surgery decreases the risk of recurrence in mutation carriers. Others may be driven by the fear of cancer that grips our society or other psychological and social factors. Although genetic variants are rarely determinative, messages about the inexorability of disease if one has mutations can be particularly strong. At a meeting several years ago, for example, an eminent geneticist said that if he were a woman who had a mutation in BRCA1, he would immediately get a bilateral mastectomy and oophorectomy<sup>10</sup> no matter what his age or cancer status. These are strong words. One interesting effect of considering genetic testing is that Iphigenia almost surely would have had much more conversation with her providers than usually occurs between physician and patient because of the norms of non-directiveness and attention to personal values that are almost uniquely espoused in the setting of genetic counseling and cancer genetics.

In his book, Jay elegantly described the intrapsychic forces that lead patients to have magical expectations, such as their desires to be taken care of in ways that they wish or believe they had been as children and their tendency to see physicians as more powerful than they actually are.<sup>11</sup> He also pointed out the chronic tendency of medicine to promise more than it can possibly deliver, an issue to which I shall return later. But the last variant of Iphigenia's story illustrates another important factor, namely the ways in which social understandings of disease affect the ability of physicians and patients to communicate effectively. Here is one place where seeing medicine as situated in a complex social web is particularly important. When I was a child, people did not talk about cancer. It was seen as embarrassing or too scary. Today, many people tell the world that they have or have had cancer, often using this fact as a rallying cry. One needs only look around to see yellow "LIVESTRONG" wrist bands and the rainbow of ribbons or think of the leaders of the National Breast Cancer Coalition who proudly proclaimed their efficacy in obtaining funding for research. But the fear of cancer is still larger than life. Physicians know that people dramatically overestimate their likelihood of developing or dying of cancer, especially in comparison with other causes.<sup>12</sup> This may lead people to

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9. See Caryn Lerman et al., *BRCA1 Testing in Families with Hereditary Breast-Ovarian Cancer: A Prospective Study of Patient Decision Making and Outcomes*, 275 JAMA 1885 (1996); Mark D. Schwartz et al., *Impact of BRCA1/BRCA2 Counseling and Testing on Newly Diagnosed Breast Cancer Patients*, 22 J. CLINICAL ONCOLOGY 1823 (2004); Jeffrey Weitzel et al., *Effect of Genetic Cancer Risk Assessment on Surgical Decisions at Breast Cancer Diagnosis*, 138 ARCHIVES SURGERY 1323 (2003).

10. Oophorectomy is the surgical removal of the ovaries.

11. See KATZ, *supra* note 1, at 104-29.

12. Women's Fear of Heart Disease Has Almost Doubled in Three Years, but Breast Cancer

make decisions that on their face seem irrational given the statistics, perhaps to the dismay of clinicians.

The public also tends to see genetic variation as more determinative of health and personal characteristics than it really is. Some of this perception may be attributable to public culture, to movies like *Gattaca*, to numerous novels, or to cartoons that show “genes” for willingness to pay \$3.75 for a cup of coffee at Starbucks. Much of the responsibility, however, resides with the scientific community itself, when investigators tout the importance of their new findings. They often carelessly refer to the “gene for” *X* disease or fail to acknowledge other factors that contribute to the appearance of illness. Conversation may be impeded by the unwarranted sense of the inexorability of biology that both clinicians and patients sometimes have.

Jay pointed out in his book that patients often have different views about the causes and therapies for diseases than their physicians. He cited, for example, Solzhenitsyn’s story in *Cancer Ward* about Kostoglotov, who wished to treat his malignancy with “a mandrake root from Issyk Kul” instead of the recommended therapy.<sup>13</sup> The prevalence and impact of these different understandings is now much clearer. The National Center for Complementary and Alternative Medicine (CAM) reported this year that of more than thirty thousand people interviewed in the United States, “36% of adults are using some form of CAM. When megavitamin therapy and prayer specifically for health reasons are included in the definition of CAM, that number rises to 62%.”<sup>14</sup> Although the majority of people said that they used CAM in addition to conventional medicine, thereby creating the potential for adverse interactions, physicians often do not ask about these interventions, and patients may not reveal them even if asked. Kostoglotov chose not to disclose his plans to his oncologist, knowing that she would not agree and might even force him to accept further radiation.

And these are not the most dramatic conflicts that can occur in a country as culturally diverse as ours. In her heart-rending book, *The Spirit Catches You and You Fall Down*,<sup>15</sup> Anne Fadiman recounts the tale of a young Hmong girl with an intractable seizure disorder. Her physicians fought to control her seizures and were frequently frustrated that she was not receiving her medications at home.

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Remains Most Feared Disease, [http://www.nhlbi.nih.gov/health/hearttruth/press/fear\\_doubled.htm](http://www.nhlbi.nih.gov/health/hearttruth/press/fear_doubled.htm) (last visited Jan. 19, 2006) (explaining that heart disease and lung cancer cause more deaths than breast cancer).

13. KATZ, *supra* note 1, at xlii.

14. NAT’L CTR. FOR COMPLEMENTARY & ALTERNATIVE MED., NAT’L INSTS. OF HEALTH, THE USE OF COMPLEMENTARY AND ALTERNATIVE MEDICINE IN THE UNITED STATES 2 (2004), available at <http://nccam.nih.gov/news/camsurvey1014.pdf>.

15. ANNE FADIMAN, *THE SPIRIT CATCHES YOU AND YOU FALL DOWN: A HMONG CHILD, HER AMERICAN DOCTORS, AND THE COLLISION OF TWO CULTURES* (1998).

They later discovered that her parents had a hard time understanding the instructions and in any event believed that seizures were not a disorder but rather were caused by a wandering soul or evil spirits, problems which could only be addressed by animal sacrifices or special ceremonies.

Although Fadiman's book is a particularly stark demonstration that allopathic medicine has its own culture or worldview, similar although usually less daunting cultural barriers to conversation occur all the time, whether clinicians recognize it or not.<sup>16</sup> Some of these clashes have been documented eloquently either by patients and their families or by those who speak on their behalf in such works as *The Long Dying of Baby Andrew*,<sup>17</sup> recounting the prolonged course of a premature baby in a neonatal intensive care unit, and *People Like That Are the Only People Here*,<sup>18</sup> Lorrie Moore's semi-autobiographical story about having a young child with cancer. In both cases, the parent-narrators experienced the health care system as deeply alienating; they were not comfortable with the course of care and felt judged as a result. Medical schools are struggling to find ways to give students and clinicians the tools to surmount these barriers.<sup>19</sup>

Clinicians, of course, are not patients' sole sources of information about health and health care. When I see an eighteen-month-old brought in for in-toeing, it is generally not the parent who is primarily concerned. Usually there is a grandmother who, remembering practice in the past, thinks that the child needs orthopedic shoes or even Denis Browne splints. In the intervening years, we have learned that in-toeing is almost always a normal developmental process and that the prior practices are actually harmful. Most children outgrow in-toeing, and most of those who don't, like Michael Jordan, tend to do fine. Yet other "knowledges" like those of the grandmother in this case are ubiquitous in pediatrics. You have to know them in order to address them, but how you act on this knowledge varies. Sometimes it is a matter of advising the parent what to tell the grandmother, and sometimes the best thing to do is to fold your cards.

The health care system itself poses formidable barriers to conversation. Many scholars have written about the role of informed consent in an era of managed care.<sup>20</sup> One basic question is if plans will pay only for certain

16. Janelle S. Taylor, *Confronting "Culture" in Medicines' "Culture of No Culture"*, 78 ACAD. MED. 555 (2003).

17. ROBERT STINSON & PEGGY STINSON, *THE LONG DYING OF BABY ANDREW* (1983).

18. LORRIE MOORE, *BIRDS OF AMERICA* (1998).

19. See, e.g., Renee C. Fox, *Cultural Competence and the Culture of Medicine*, 353 NEW ENGL. J. MED. 1316 (2005); Elizabeth K. Kachur & Lisa Altshuler, *Cultural Competence Is Everyone's Responsibility!*, 26 MED. TCHR. 101 (2004).

20. See, e.g., Mark A. Hall, *A Theory of Economic Informed Consent*, 31 GEORGIA L. REV. 511 (1997); Joan H. Krause, *Reconceptualizing Informed Consent in an Era of Health Care Cost*

interventions and if patients tend to use only those therapies for which third party payment is available given the high cost of medical care, what if anything needs to be disclosed about non-covered options? Some argue that disclosing the rationing or allocation strategy at the time of entry into the plan is sufficient, while others urge that the increasing importance of economic incentives and limits of coverage increase the urgency of disclosure at the time when decisions are being made about intervention. No consensus has emerged, and in any event, the pressure on physicians to see more patients, many of whom have multiple medical problems, means that there is often little time to talk.<sup>21</sup>

Twenty years ago, Jay urged that we ought to be able to have more useful dialogue because so much more was known about the etiology of disease and how to treat it. Still more information is available today, but new knowledge does not necessarily promote shared decision-making. Much remains unknown. Indeed, the watchword of today's science is complexity: the recognition that it is never possible to specify all the factors that influence an individual clinical case. As has always been true, clinicians have a hard time keeping up with what actually is known, and as a result, frequently cause injuries that could otherwise have been avoided. In part to help physicians with this flood of information, organizations are now creating tools such as clinical practice guidelines, typically based on rigorous review of the medical literature and expert opinion. These tools, however, rarely give much weight to the importance of patients' wishes and values, usually focusing instead on such readily quantifiable outcomes as longevity, disease-free survival, and the incidence of adverse side effects. Efforts are being made to incorporate measures of patients' opinions into assessments of care,<sup>22</sup> but in a time when these instruments increasingly are being used as metrics to assess clinicians' actions, the failure to attend sufficiently to patients' values looms large. Returning to Iphigenia, suppose she had a germline mutation in BRCA1, and the evidence showed that bilateral mastectomy would optimize her chance of disease-free survival. Could there come a time when the medical community would consider her surgeon to be practicing substandard medicine and the hospital and third party payer would penalize him were he to perform a lumpectomy with subsequent radiation? How might this affect their conversation?

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*Containment*, 85 IOWA L. REV. 261 (1999); Susan M. Wolf, *Toward a Systemic Theory of Informed Consent in Managed Care*, 35 HOUST. L. REV. 1631 (1999).

21. The average outpatient visit lasts fifteen to twenty minutes, with longer duration being associated with more testing and admission to the hospital. David Blumenthal et al., *The Duration of Ambulatory Visits to Physicians*, 48 J. FAM. PRAC. 264 (1999); David Mechanic et al., *Are Patients' Office Visits with Physicians Getting Shorter?*, 344 NEW ENGL. J. MED. 198 (2001).

22. Mark Sullivan, *The New Subjective Medicine: Taking the Patient's Point of View on Health Care and Health*, 56 SOC. SCI. MED. 1595 (2003).



The constraints on physicians posed by managed care and evidence-based medicine are simply more recent manifestations of the conflicts of interest that pervade the practice of medicine, which Jay so perceptively but too gently described in his book. Physicians for millennia have promised to be devoted solely to the interest of each particular patient. A few years ago, the institution in which I practice required its practitioners to affirm that we would place our patients' interests above our own. Hundreds of us signed our names on wall coverings, which were then hung in a main hallway to demonstrate our commitment. This, however, is a promise that cannot be kept. Practitioners have always had to balance the demands of any particular patient against the needs of other patients, their families, their communities, and themselves. Clinicians have always been influenced by the broader society for both good and ill, the latter as evidenced by the impact of discriminatory attitudes. Even the issues of cost and effects of reimbursement, so prominent in today's debates about health care, have always been problems. Unless these competing claims and forces are acknowledged, it is not possible to decide how they are to be balanced so that the physician can realistically inform the patient about what care the doctor can and cannot provide.

Here is where, for me, Jay's most important contribution appears. It is easy for physicians to say that patients have all kinds of magical, irrational, contradictory, and counterfactual beliefs and expectations. After all, we say patients are ignorant of medicine and their diseases cause them to regress. It is quite another to admit that physicians are not always rational either. They, too, are influenced by intrapsychic phenomena, such as transference and countertransference. Jay illustrated these influences beautifully in his recounting of the interactions between Dr. Christian Barnard and Philip Blaiberg, in which Barnard asked Blaiberg to undergo the second heart transplant ever attempted in order to help *Barnard* get his confidence back after the death of Louis Washkansky, the first transplant recipient.<sup>23</sup> Happily, Blaiberg did well after his transplant, but it was clear that Barnard was driven to some extent by his own needs. Dr. Barnard is not unique in this regard. Most clinicians have complex reasons for going into medicine. We receive all sorts of gains from our practice, both economic and personal, some of which can affect the ways in which we see or treat our patients.

Physicians have a remarkable ability to deny the forces that influence them. To pick one of my pet peeves, large pharmaceutical companies now spend more than \$12 billion per year on drug detailing, that is, efforts to educate providers about new products. It should be no surprise that this detailing influences

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23. KATZ, *supra* note 1, at 130-33.

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prescribing.<sup>24</sup> Companies do not thrive if they waste money on that grand a scale. Physicians, however, persist in believing that they are unaffected by these practices.<sup>25</sup> Although medical associations have issued guidelines that limit detailing and gift giving,<sup>26</sup> many physicians see these activities as at worst modestly problematic.<sup>27</sup> It is difficult to change behavior if the actors deny its causes.

Medicine also poses numerous stresses, and physicians do not deal with all of these tensions equally well. Physicians often react badly to uncertainty, as Jay documented in his extended colloquy about the history of breast cancer treatment with its heated battles over the appropriate type of surgery.<sup>28</sup> He pointed out that clinicians typically are trained to act as if the appropriate interventions are clear. There are two points in that sentence. One is the emphasis on action; it is hard to sit and watch. And acting is more comfortable if one is confident about what one is going to do. But despite the enormous advances in science, uncertainty has not gone away. The topics have changed, the number of questions has grown, and yet the pressure to act and act quickly has increased.

Physicians hate it when their patients do not do well. It can be hard to go talk with someone whose health is declining. As Jay demonstrated in the story of his mother's abandonment by her physician<sup>29</sup> and as all clinicians know, the doctor's first response to bad news is typically one of avoidance. This reaction is even stronger when the patient's worsening course is the result of a mistake. While this is hardly surprising, failing to talk with patients makes them very angry. In research we conducted at Vanderbilt University more than a decade ago, parents whose children had suffered perinatal injuries often said that they sued because they believed that information was being withheld or that they simply wanted to find out what had happened. With regard to the physician-patient relationship, the respondents reported that "physicians would not listen (13% of sample), would not talk openly (32%), attempted to mislead them (48%), or did not warn about long-term neurodevelopmental problems (70%)."<sup>30</sup> For purposes of

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24. Ashley Wazana, *Physicians and the Pharmaceutical Industry: Is a Gift Ever Just a Gift?*, 283 JAMA 373 (2000).

25. Kerry J. Breen, *The Medical Profession and the Pharmaceutical Industry: When Will We Open Our Eyes?*, 180 MED. J. AUSTL. 409 (2004).

26. Am. Med. Ass'n, *Ethical Opinions and Guidelines on Gifts* (2004), <http://www.ama-assn.org/ama/pub/category/4001.html> (last visited August 30, 2004).

27. Allan S. Brett et al., *Are Gifts from Pharmaceutical Companies Ethically Problematic? A Survey of Physicians*, 163 ARCHIVES INTERNAL MED. 2213 (2003).

28. KATZ, *supra* note 1, at 175-84.

29. *Id.* at 223-24.

30. Gerald B. Hickson et al., *Factors That Prompted Families to File Medical Malpractice Claims Following Perinatal Injuries*, 267 JAMA 1359 (1992).

understanding why people sue, claimants' perceptions are all that matter. As Marshall McLuhan might say in this setting, "perception is reality." But in all likelihood, these complaints contained more than a grain of truth.

The first step to addressing the barriers to communication that physicians face is to recognize their presence. As Jay so clearly instructed, this can only be achieved by self-reflection. Even then, a person's ability to know what motivates her will always be incomplete. There are clues, though, to when the doctor should try harder. The most powerful clue is a desire to avoid conversation, a feeling that often indicates that more dialogue is needed.

But here is where the rub really comes. For most physicians, and I include myself here, the kind of respectful, self-aware attention to the needs and interests of patients that Jay called for is simply not possible much of the time. The easy excuses are that the medical system is not set up to accommodate prolonged mutual exploration of options and that the costs in terms of lost revenues would be exorbitant. Jay explicitly declined to consider the issue of costs at any length,<sup>31</sup> but he did point out the costs of not talking can be high as well.

The more difficult problem is that most of us simply do not have adequate communication skills or the thoroughgoing respect for others that Jay would have us demonstrate. These are goals to which we should aspire, but I would suggest, perhaps heretically, that this is a promise that cannot be fulfilled. We humans generally lack the capacity to achieve that level of awareness of self and other even in our closest relationships, to say nothing of across the gulf between physician and patient. In this regard, Jay's vision of informed consent raises some of the same magical expectations of care that he so clearly identified and urged us to challenge.

There also are competing interests that legitimately interfere with the ability to meet the needs of individual patients. Other patients have needs as well, for both attention and resources. Allocation is necessary in medicine as in all other aspects of life, but the fear of the "r" word—rationing—has made it difficult to engage in reasoned analysis. In addition, Jay acknowledged that physicians' personal needs can conflict with and, on occasion, even justify overriding the wishes of patients.<sup>32</sup> Attempting to address the psychosocial aspects of medicine can be exhausting and is certainly among the most challenging parts of practice. I have found that I can attend effectively on the inpatient service of the hospital for only a few weeks at a time. The time commitment of being on call is difficult, but it pales in comparison to trying to meet the emotional, educational, and medical needs of patients, their families, residents, and students. These efforts take a toll on family, friends, and other obligations. Every day is a lesson in humility,

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31. KATZ, *supra* note 1, at 227-28.

32. *Id.* at 162-63.

especially if one thinks about the goals that Jay set for us.

The most thoughtful physicians I know squirm when they read Jay's work. The more thoughtful they are, the more they squirm. If you think about it, the job of attending to the emotional aspects of clinical care is impossible. We are parts of a complex network, and our ability to act is both constrained and enabled by forces in and outside of ourselves. Autonomy is relative, not absolute. Jay described numerous problems and vast silences. More have emerged since he wrote *The Silent World*, only some of which I have addressed in this paper. And while the law has at least brought attention to the issue of informed consent and scared physicians half to death, it actually has done little to protect patients' interests in shared decision-making. The courts do not award compensation for dignitary injuries alone, which are the primary result of silence. State legislatures, in general, have been even less protective of patients' interests, enacting explicit but limited criteria for what needs to be disclosed. And lawyers have created a sea of consent forms that sinking patients rarely read. As Jay clearly pointed out, courts speak of "reasonable physicians" and "reasonable patients" when the real world issues are always about individuals who exhibit both reason and unreason and who fail to communicate.

But in closing, I would like to point to more positive aspects of the physician-patient relationship, which can promote at least some aspects of the care to which Jay aspires. In this regard, the web in which we live and work can support our interactions with patients. Here, I will speak primarily from my own experience as an academic general pediatrician. It is really wonderful when your patients get better, especially when something you did helped the process. (One of the reasons I like pediatrics is that kids have an amazing ability to get better no matter what you do.) And getting to talk with children and parents can be a real joy. Somewhere I heard that children do better in school if their physicians ask them about how they are doing and find something to praise. I do not know if this works or not, but it sure is fun, and it gives parents a chance to brag about their kids and kids a chance to be acknowledged by another adult in front of their parents. I encourage all the residents and students I work with to do this as well. As the possibility of conversation increases with a child's age, it is gratifying to help adolescents deal with injury, illness, and normal development. This is a setting where it can be emotionally fulfilling to talk with a teenager!

Many of the greatest rewards come from talking with parents. Often, the issues seem minor from a medical perspective, but for the parents, they can be emotionally draining. A while ago, I saw a young girl with a unilateral tender breast mass. Puberty now occurs earlier in childhood and usually begins with breast development, which is often asymmetric. Most mothers do not remember every aspect of their own bodily transformation. A brief conversation revealed that this mother was worried that her daughter had breast cancer. The child was

not yet a reader, so I said simply, “It is extremely unlikely that your child has C-A-N-C-E-R.” You can imagine the relief that came over the mother’s face. We then went on to talk about what was probably happening and to develop a plan for follow up.

The practice of pediatrics is about empowering children and their families. Most of the time, sick children are not in the hospital. They may come to the pediatrician to find out what is wrong, but what happens next requires collaboration between parent and physician. The doctor can prescribe an antibiotic for a bacterial infection, but she will not be the one to give it. The parent may not be able to afford the medicine, may not have the time to go get it or give it (it is hard to administer medications four times a day when you work outside the home and your child goes to school), may doubt the efficacy of that particular drug (Joey did not get better on amoxicillin last time), or may be pursuing alternative interventions at the same time. All these factors have to be negotiated. Older children are part of the mix as well. The young teen with asthma needs to take his medications and to let his parents know when he develops breathing problems so that they can seek care in a timely fashion. This can be a challenge given the psychological issues that often attend adolescence. Collaboration is important even when children are in the hospital. Parents can provide critical emotional support for their child. They can help mediate the interactions between their child and the host of providers they encounter. And sometimes, parents discover mistakes, either after or preferably before they occur.

Why do we do all this talking and negotiating? The reasons are complex and vary in their nature. Some are deontological, some are utilitarian, and some are personally reinforcing for the physician. Talking is the right thing to do. Medical care implicates values and concerns that can only be elicited through conversation. Collaboration leads to better outcomes. Parents and children are calmer and more adherent to the course of action ultimately agreed upon. Communication can be gratifying all by itself. It makes me feel good when I connect with a parent or a child.

What it comes down to is this. Despite the advances in technology, medicine is still intensely personal. Computer interviewing is making inroads, but human beings are still better at getting the history of what patients are experiencing, which remains a key to diagnosis. Even though patients and their families now have unparalleled access to information through the Web and other places, they frequently prefer to receive counseling from a clinician.<sup>33</sup> Respectful shared

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33. Michael J. Green et al., *Effect of a Computer-Based Decision Aid on Knowledge, Perceptions, and Intentions About Genetic Testing for Breast Cancer Susceptibility: A Randomized Controlled Trial*, 292 JAMA 442 (2004).

THE WEB OF RELATIONS

decision-making is difficult, and truthfully, impossible much of the time. The networks in which physicians and patients live both impede and promote needed conversation. Jay's great gift to us is that he identified some of the barriers and potholes so we can try to do better.



## Response

### From Tragedy to Catastrophe: Lawyers and the Bureaucratization of Informed Consent

Alan Meisel, J.D.\*

I have not seen Jay in more than ten years—when he accepted an invitation to speak in Pittsburgh. I also have not thought about informed consent much in the last ten or fifteen years, with the exception of a single moment of weakness when I succumbed to a colleague's entreaties to co-author a paper on the subject a few years ago. My ambivalence about informed consent has nothing—and everything—to do with Jay. My reluctance to continue to engage the subject resulted from my belief that everything important to say about informed consent had already been said, endless times, and by people far wiser than I, most notably Jay Katz. And, so I thought, not only had everything been said, so little had been achieved—at least judging from my own experiences with doctors, both as a patient and as a teacher, and the reports of friends and family members. Having read Ellen Wright Clayton's paper, *The Web of Relations: Thinking About Physicians and Patients*,<sup>1</sup> I can see that I was wrong. Not everything had been said.

For me to talk about informed consent is therefore a labor of love. A labor of love out of respect for a doctor—in the original meaning of the word: teacher—who kindled a flame in me possibly before he had even heard of informed consent himself.

Long ago and in another century when I was a sophomore or junior at Yale, Branford College, of which I was a resident, sponsored an evening lecture. Whatever its title was, it was enticing enough to assure my attendance, where I heard a speaker talk about something, to use the parlance of the time, that really turned me on.

A few years later, when beginning my second year of law school within the

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1. Ellen Wright Clayton, *The Web of Relations: Thinking About Physicians and Patients*, 6 YALE J. HEALTH POL'Y L. & ETHICS 465 (2006).



walls of Yale, and needing another course to register for, I ran across one called “Experimentation with Human Beings.” The professor’s name immediately rang a responsive chord; it was that gentleman whose talk I had enjoyed a few years earlier at Branford. I registered for that seminar. And that’s why I’m here today, rather than working on Wall Street. The year was 1970, thirteen years after the first case to use the term “informed consent,” the *Salgo* case,<sup>2</sup> but still a couple of years before *Canterbury v. Spence*,<sup>3</sup> *Cobbs v. Grant*,<sup>4</sup> and the tidal wave of informed consent litigation that they spawned.

In *Silent World*, Jay recognizes the distinction between the *idea* of informed consent and the *legal doctrine* of informed consent.<sup>5</sup> This paper discusses another chapter in the tale of informed consent. Jay wrote so eloquently about what happened to the idea of informed consent when it fell into the hands of lawmakers. This response discusses what happened to the legal doctrine of informed consent when it fell into the hands of lawyers and health care managers.

In her paper, Ellen Wright Clayton observed that “[h]appily, the notion of shared decision-making has made sufficient inroads today that it would be uncommon to find a chorus of physicians who would publicly admit that it was crazy to let Iphigenia make her own choice.”<sup>6</sup> Shared decision-making is certainly more common than it was two decades ago, but like Clayton, I seriously doubt that it is anything like the universally operative paradigm. I would venture to guess that, in fact, it is still a fairly rare bird. Rather, what commonly passes for informed consent today is often a withered and bureaucratized version of shared decision-making. What passes for informed consent today is too often the same as it was twenty, thirty, or forty years ago—namely: “sign here.” Except, rather than signing the single piece of paper of a generation or two ago, patients are now asked to sign a novel-, or at least a novella-, length document.

We moved from the lofty idea of informed consent circa 1960, to the informed consent form, in a quarter century, give or take a few years—a cautionary tale if there ever was one. In fact, as early as 1966, early enough to be included in Jay’s *Experimentation with Human Beings*, a physician gave us a humorous example of what was to come:

Consent Form for *Hernia* Patients:

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2. *Salgo v. Leland Stanford Jr. Univ. Bd. of Trs.*, 317 P.2d 170 (Cal. Ct. App. 1957).

3. *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972).

4. *Cobbs v. Grant*, 502 P.2d 1 (Cal. 1972).

5. JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 48-84 (Johns Hopkins Univ. Press 2002) (1984) [Hereinafter KATZ, *SILENT WORLD*].

6. Ellen Wright Clayton, *The Web of Relations: Thinking About Physicians and Patients*, 6 YALE J. HEALTH POL’Y L. & ETHICS 465, 466-67 (2006).

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*Operative procedure* is as follows: The doctor first cuts through the skin by a four-inch gash in the lower abdomen. He then slashes through the other things—fascia (a tough layer over the muscles) and layers of muscle—until he sees the cord (tube that brings the sperm from testicle to outside) with all its arteries and veins. The doctor then tears the hernia (thin sac of bowels and things) from the cord and ties off the sac with a string. He then pushes the testicle back into the scrotum and sews everything together, trying not to sew up the big arteries and veins that nourish the leg.<sup>7</sup>

He then set out fifteen possible complications, including such things as: “[l]arge artery may be cut and I may bleed to death . . . [,] tube from testicle may be cut. I will then be sterile on that side . . . [, and] I may be run over going to the hospital.” Following that list, there are signature lines for the patient, the patient’s lawyer, the lawyers for the hospital, the doctor, the anesthesiologist, and to underscore the absurdity, a signature line for the patient’s mother-in-law.<sup>8</sup>

In *Silent World*, Jay was concerned about the gulf between the idea of informed consent and the manner in which courts had translated this idea into legal rules—rules that go far in undermining the idea itself. If the manner in which the law undermines the idea of informed consent through such aspects of the legal doctrine as the standard of disclosure, the materialized risk requirement, and the therapeutic privilege, to name just a few, is a tragedy, what has been done in the name of operationalizing informed consent by lawyers and health care managers is a catastrophe. The courts (and later the legislatures) may have eviscerated the idea of informed consent, but they left it to the health care managers—and the lawyers who counsel them—to bury the eviscerated remains.

Consider as an example the question that has been asked countless times by every attending to every resident: “Did you get the patient consented?” I don’t know what is more dispiriting: the language which treats the patient as an object rather than a subject and transforms what should be a process into an event (and butchers the English language all at the same time); or the fact that it is the house staff who play the major role in this process, or event, or whatever one calls it—rather than the senior attending physician who should be doing it and modeling it for the house staff.

Informed consent in practice today is certainly different from the simple, paternalistic days of yore that Jay decried in *Silent World*. I hope and believe that, on balance, more of today’s physicians make a genuine effort to provide

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7. Preston J. Burnham, *Medical Experimentation on Humans*, 152 *SCIENCE* 448 (1966), reprinted in JAY KATZ, *EXPERIMENTATION WITH HUMAN BEINGS* 659 (1972).

8. *Id.*

patients with information about their options. But different is not necessarily better. The aim of informed consent, as it has been translated into action in the clinical setting today, is just an updated and more sophisticated version of its precursor in the traditional doctor-patient relationship: to make the patient reliant on the doctor; to assure that the doctor's wishes will prevail, and that the patient will not independently develop wishes or that any such wishes will not become manifest.

In the good old paternalistic days, this goal was achieved in significant part by nondisclosure and possibly by a reassuring statement from the doctor such as, "Let me worry about that." Today, the form has changed—indeed, it has changed 180 degrees—but the message is the same. Today, the byword is disclosure—but the doctor's purpose is often the same. Thus, the emphasis is on "getting the patient consented"—i.e., getting a signed consent form for the intern to bring back to the resident like a set of antlers from a safari. Often, informed consent takes the form of a medical *Miranda* warning in which risk disclosure substitutes for conversation. That way, if something goes wrong, it is the patient's responsibility and not the doctor's. This converts an affirmative duty of doctors into a defense of assumption of risk against patients.

By contrast, informed consent can be viewed as a medical cafeteria, in which the options are laid out in front of the patient and the patient directed to choose. What is missing from this picture is a lack of advice by the doctor, an abdication of moral responsibility just as surely as failing to disclose would be. Alternatively, informed consent can become an exercise in "information dumping." Overload the patient with information, thereby complying with the letter of the law but undermining the idea of informed consent. And putting it in writing reduces the chance of discussion even more. Finally, the *idea* of informed consent—as well as the more modest goals of the law—can readily be subverted by providing information but providing it at a level of complexity aimed at undermining understanding rather than enhancing it.

Twenty years ago, Jay set forth a vision of a better world and of a better doctor-patient relationship. He pointed out to us—among other things—the tragedy of what the law had done to a noble idea. Today, twenty years later, in some respects things have gotten worse.

What or who is responsible for this? Doctors are the usual whipping-boys, being frequently criticized, as I have done, for their wooden approach to providing information to patients. In fairness, most times they are just following lawyers' orders, either their own lawyers or hospital or nursing home lawyers—to get it in writing and to give it in writing, too. The lawyer's standard advice—"Document it; if it's not in writing, it didn't happen"—sometimes comes directly from a lawyer; other times it is filtered through institutional health care managers.

Not only, as Ellen Wright Clayton observed, does medicine have *its* own culture or world view which creates barriers to conversation,<sup>9</sup> so too does the culture of lawyers. Part of this culture—especially when giving advice to clients about matters to be carried out repeatedly, over indefinite periods of time, and by many people—tends towards the bureaucratic. So if the handiwork of judges and legislators is not enough to undermine the idea of informed consent, the handiwork of lawyers and their clients—health care managers through whose hands lawyers’ advice passes—administers the coup de grace. The awkwardly and hopefully named “informed consent form” epitomizes this. As lawyers became increasingly aware of the necessity for doctors not only to obtain consent from patients but first to provide them with information that can be used in making a decision whether to consent or not, lawyers rightly advised their clients—both individual health care professionals and health care institutions—to disclose this kind of information. But instead of focusing on the goals that the requirement of obtaining informed consent sought to promote—patient self-determination, informed decision-making, and protection from harm chief among them<sup>10</sup>—lawyers instead focused on *documenting* whether information had been disclosed, even if in fact it had not been. Thus the centerpiece of informed consent became the consent form rather than the process of disclosure—and the opportunity it provided for discussion between physician and patient.

The challenge for us—twenty years after the publication of *Silent World*, almost fifty years since the phrase informed consent was first uttered in a judicial opinion—is how to reclaim Jay’s vision and make it a reality. I am afraid that we as doctors, as lawyers, and as health care managers still have much for which to strive in order to achieve that vision.

Those of us in legal education—especially those of us who were inspired by Jay—have a special responsibility to him and to his intellectual legacy, not to mention to patients and even to doctors. Our responsibility is to educate the next generation of lawyers to practice law—especially to counsel clients—with as much wisdom as Jay urged physicians to use to counsel patients. Perhaps then, the next generation of lawyers can begin to contribute to a genuine collaboration between doctors and patients. I can think of no more fitting a way to honor Jay from all of us—his daughters and sons in law.

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9. Clayton, *supra* note 1.

10. See JAY KATZ, *SILENT WORLD*, *supra* note 5.



## Response

### Doctor and Patient: An Unfinished Revolution

Susan M. Wolf, J.D.\*

The second half of the twentieth century saw an attempt to revolutionize the doctor-patient relationship. Jay Katz's work has been pivotal.<sup>1</sup> Professor Katz himself has dubbed his proposal to upend millennia of Hippocratic silence and paternalism "radical."<sup>2</sup> Radical it is, trading physician silence for openness even about the physician's uncertainty, substituting joint decision-making by doctor and patient for physician solo decision-making, and in cases of conflict recognizing the patient's dominion over her own body.

Just how radical this proposal is has become even more apparent since Katz published *The Silent World of Doctor and Patient*<sup>3</sup> in 1984.

First, a raft of empirical research has documented continued physician

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1. JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (Johns Hopkins Univ. Press 2002) (1984) [hereinafter KATZ, *THE SILENT WORLD*]; Jay Katz, *Disclosure and Consent: In Search of Their Roots*, in *GENETICS AND THE LAW II*, at 121 (Aubrey Milunsky & George J. Annas eds., 1980); Jay Katz, *Informed Consent: Legal and Ethical Aspects*, in 2 *ENCYCLOPEDIA OF BIOETHICS* 770 (Warren T. Reich ed., 1978); Jay Katz, *Informed Consent—A Fairy Tale? Law's Vision*, 39 *U. PITT. L. REV.* 137 (1977); Jay Katz, *Informed Consent: Must It Remain a Fairy Tale?*, 10 *J. CONTEMP. HEALTH L. & POL'Y* 69 (1993) [hereinafter Katz, *Informed Consent: Must It Remain a Fairy Tale?*]; Jay Katz, *Limping Is No Sin: Reflections on Making Health Care Decisions*, 6 *CARDOZO L. REV.* 243 (1984); Jay Katz, *Physician-Patient Encounters "On a Darkling Plain"*, 9 *W. NEW ENG. L. REV.* 207 (1987); Jay Katz, *Why Doctors Don't Disclose Uncertainty*, *HASTINGS CENTER REP.*, Feb. 1984, at 35.

2. Katz, *Informed Consent: Must It Remain a Fairy Tale?*, *supra* note 1, at 84.

3. KATZ, *THE SILENT WORLD*, *supra* note 1.

reluctance to talk to patients about treatment options.<sup>4</sup> Data further show physician failure to follow patient preferences, even when explicitly articulated orally or in writing.<sup>5</sup> The definitive study remains the Study to Understand Prognoses and Preferences for Outcomes and Risk of Treatments (SUPPORT) by Joanne Lynn, Joan Teno, and colleagues.<sup>6</sup> The SUPPORT research shows that

4. Alfred F. Connors et al. (The SUPPORT principal investigators), *A Controlled Trial To Improve Care for Seriously Ill Hospitalized Patients*, 274 JAMA 1591, 1595 (1995) (finding that even the SUPPORT intervention did not increase the proportion of patients or surrogates who succeeded in having a discussion with their doctor about end-of-life treatment choices); Jan C. Hofmann et al., *Patient Preferences for Communication with Physicians About End-of-Life Decisions*, 127 ANNALS INTERNAL MED. 1 (1997) (“Physicians . . . are frequently unaware of patient preferences for end-of-life care; this suggests that communication about these issues may be inadequate.”); Harlan M. Krumholz et al., *Resuscitation Preferences Among Patients with Severe Congestive Heart Failure*, 98 CIRCULATION 648, 653 (1998) (“Despite the fact that these patients were very ill and their physicians expected many of them to die within the next 2 months, we found that only about one quarter of the patients and physicians reported that they had discussed resuscitation issues.”).

5. Connors et al., *supra* note 4, at 1596 (“In phase II of SUPPORT, improved information, enhanced conversation, and an explicit effort to encourage use of outcome data and preferences in decision-making were completely ineffectual, despite the fact that the study had enough power to detect small effects.”); Marion Danis et al., *A Prospective Study of Advance Directives for Life-Sustaining Care*, 324 NEW ENG. J. MED. 882 (1991) (finding that advance directives may be ignored or overridden in the clinic); Paul Haidet et al., *Outcomes, Preferences for Resuscitation, and Physician-Patient Communication Among Patients with Metastatic Colorectal Cancer*, 105 AM. J. MED. 222, 227 (1998) (“Where a conversation between physician and patient was reported, physician understanding of patients’ preferences was not better than in those instances when such a conversation had not occurred.”); Joan M. Teno et al., *Do Advance Directives Provide Instructions That Direct Care?*, 45 J. AM. GERIATRICS SOC’Y 508 (1997) [hereinafter, Teno et al., *Do Advance Directives Provide Instructions That Direct Care?*] (suggesting that advance directives do not help communication and do not guide medical decision-making); Joan M. Teno et al., *Do Formal Advance Directives Affect Resuscitation Decisions and the Use of Resources for Seriously Ill Patients?*, 5 J. CLINICAL ETHICS 23 (1994) [hereinafter Teno et al., *Do Formal Advance Directives Affect Resuscitation Decisions and the Use of Resources for Seriously Ill Patients?*] (finding that advance directives did not affect decision-making on resuscitation for seriously ill patients).

6. The SUPPORT team has published a number of studies. *See, e.g.*, Connors et al., *supra* note 4 (suggesting that enhancing communication between doctors and patients may not be enough to change end-of-life practices); Kenneth E. Covinsky et al., *Communication and Decision-Making in Seriously Ill Patients: Findings of the SUPPORT Project*, 48 J. AM. GERIATRICS SOC’Y S187-93 (2000) (reviewing the published articles from SUPPORT and concluding that there is poor communication between patients, physicians, and surrogates but that deficiencies in communication are not likely to be corrected by a simple intervention); Hofmann et al., *supra* note 4 (showing that most patients do not discuss end-of-life options with physicians even though they may want to do so); Russell S. Phillips et al., *Findings from SUPPORT and HELP: An Introduction*, 48 J. AM.

even when patients express their preferences about big-ticket items such as life-sustaining treatment, and even when the patient is assigned a nurse-advocate to champion those preferences, it does not work.<sup>7</sup> Physicians continue marching down the treatment path they choose.

Moreover, there is reason to fear that the gulf between doctor and patient and the barriers to change are even worse when the physician is white and the patient is a person of color.<sup>8</sup> Study after study shows physicians offering fewer treatment

GERIATRICS SOC'Y S1 (2000) (demonstrating that physicians often do not know patients' preferences); Teno et al., *Do Advance Directives Provide Instructions That Direct Care?*, *supra* note 5 (explaining that advance directives do not help communication); Teno et al., *Do Formal Advance Directives Affect Resuscitation Decisions and the Use of Resources for Seriously Ill Patients?*, *supra* note 5 (stating that advance directives did not affect decision-making); *see also* Dale G. Larson & Daniel R. Tobin, *End-of-Life Conversations: Evolving Practice and Theory*, 284 JAMA 1573 (2000).

7. *See* Connors et al., *supra* note 4, at 1595–98.

8. *See, e.g.*, COMM. ON UNDERSTANDING & ELIMINATING RACIAL & ETHNIC DISPARITIES IN HEALTH CARE, INST. OF MED., *UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE 1* (2003) [hereinafter INST. OF MED.]; MOREHOUSE MED. TREATMENT & EFFECTIVENESS CTR., MOREHOUSE SCH. OF MEDICINE, *A SYNTHESIS OF THE LITERATURE: RACIAL AND ETHNIC DIFFERENCES IN ACCESS TO MEDICAL CARE* (1999), *available at* <http://www.kff.org/minorityhealth/upload/A-Synthesis-of-the-Literature-Racial-Ethnic-Differences-in-Access-to-Medical-Care-Report-2.pdf>; Lisa A. Cooper et al., *Patient-Centered Communication, Ratings of Care, and Concordance of Patient and Physician Race*, 139 ANNALS INTERNAL MED. 907 (2003) (finding that race-concordant visits are longer and characterized by more patient-positive affect compared with race-discordant visits); Lisa Cooper-Patrick et al., *Race, Gender, and Partnership in the Patient-Physician Relationship*, 282 JAMA 583 (1999) (finding that African Americans rate their interactions with white physicians as less participatory); Warren J. Ferguson & Lucy M. Candib, *Culture, Language, and the Doctor-Patient Relationship*, 34 FAM. MED. 353, 359 (2002) (“Minority patients, especially those not proficient in English, are less likely to engender empathic responses from physicians, less likely to establish rapport with physicians, less likely to receive sufficient information, and less likely to be encouraged to participate in medical decision making.”); Hofmann et al., *supra* note 4, at 9 (“[J]ust as nonwhites receive less intensive use of resources . . . they may also be less likely to have their needs met for discussions about care preferences at the end of life.”); Nancy L. Keating et al., *Patient Characteristics and Experiences Associated with Trust in Specialist Physicians*, 164 ARCHIVES INTERNAL MED. 1015, 1017 (2004) (finding that black patients were 18% less likely to develop a completely trusting relationship with their specialist than white patients); Thomas A. LaVeist & Tamyra Carrol, *Race of Physician and Satisfaction with Care Among African-American Patients*, 94 J. NAT'L MED. ASS'N 937 (2002) (“[P]atients who were race concordant reported higher levels of satisfaction with care compared with African American patients that were not race concordant. . . .”); Thomas A. LaVeist & Amani Nuru-Jeter, *Is Doctor-Patient Race Concordance Associated with Greater Satisfaction with Care?*, 43 J. HEALTH & SOC. BEHAV. 296, 303 (2002) (finding that patients are more satisfied with physicians of their own race than with a physician of a different race); David R. Levy, *White*



options, performing fewer treatment interventions, and listening less. The results are poorer health outcomes, psychological and physical harm, and dignitary insult.

Meanwhile, old-style Hippocratic practice remains remarkably entrenched in many quarters. Witness an article published by the *New York Times* science section in 2004. A physician offered a case report entitled *Give Up? No Way. On a Matter of Life or Death, a Patient Is Overruled*.<sup>9</sup> The article recounted a physician's decision to order an assault on a competent patient, who had persistently stated over the course of several days that he did not want to be intubated. This patient had earlier suffered a heart attack followed by cardiac catheterization. When aggressive use of blood thinners filled the patient's lungs with blood and compromised his breathing, the physician authoring this case report decided to override the patient's express rejection of intubation. "As an experienced doctor, wasn't I in a better position to make Mr. Smith's decision than Mr. Smith?"<sup>10</sup> This is classic Hippocratic paternalism, favoring the physician's assessment of what will serve the patient's well-being over the patient's choice. As the medical team forcibly intubated the patient and then put in a central line, Mr. Smith predictably became violent. What followed was a "rocky hospital course" requiring two weeks on the ventilator.<sup>11</sup> For that entire time, the physician who ordered the intubation avoided the patient's bedside. It was only after the tube was finally removed that the physician summoned the courage to go see the patient. Remarkably, the physician admits that, "[w]hen I went to see him, I realized I had never really looked at him as a person."<sup>12</sup>

Resistance to overturning Hippocratic paternalism is not limited to physicians. Judges have fallen prey as well. Katz famously diagnosed judicial ambivalence and resistance in the case law on informed consent.<sup>13</sup> As he

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*Doctors and Black Patients: Influence of Race on the Doctor-Patient Relationship*, 75 PEDIATRICS 639 (1985) (describing racial difference that may affect the doctor-patient relationship and the impact racism may have on black patients); see also Earl Ford et al., *Coronary Arteriography and Coronary Bypass Surgery Among Whites and Other Racial Groups Relative to the Hospital-Based Incidence Rates for Coronary Artery Disease: Findings from NHDS*, 79 AM. J. PUB. HEALTH 437 (1989) (finding that black men are only half as likely to undergo angiography and one third as likely to undergo bypass surgery as white men); Charles Maynard et al., *Blacks in the Coronary Artery Surgery Study (CASS): Race and Clinical Decision Making*, 76 AM. J. PUB. HEALTH 1446 (1986) (finding that surgery is recommended for whites more often than blacks).

9. Sandeep Jauhar, *Give Up? No Way. On a Matter of Life or Death, a Patient Is Overruled*, N.Y. TIMES, Oct. 5, 2004, at F5.

10. *Id.*

11. *Id.*

12. *Id.*

13. KATZ, *THE SILENT WORLD*, *supra* note 1, at 48–84.

recounts, Justice Cardozo's breakthrough announcement in 1914 that "every human being of adult years and sound mind has a right to determine what shall be done with his own body"<sup>14</sup> was followed by decades of physician and judicial silence. It was mid-century before judges returned to the question of the patient's right to decide and thus entitlement to information material to the decision.<sup>15</sup> Even then, it was slow going. Not until the 1972 decision in *Canterbury v. Spence* did a court robustly articulate the physician duty of informed consent,<sup>16</sup> and that decision, too, shows great ambivalence over tampering with physician custom and discretion.<sup>17</sup> Post-*Canterbury* many state legislatures rushed to protect physicians from what changes the courts managed to demand.<sup>18</sup>

Judicial ambivalence continues to this day. Witness *Arato v. Avedon*, decided twenty-one years after *Canterbury*.<sup>19</sup> Mr. Arato was a forty-two-year-old husband and father diagnosed with pancreatic cancer. Despite seventy visits to the oncologist, he was never told the dismal survival statistics associated with his cancer. Nor was he told when the physicians offered him a rigorous chemotherapy and radiation regimen that had "shown promising response rates" in experimental trials that this regimen would at best extend his life a few months.<sup>20</sup> After Mr. Arato's death his wife and children sued, arguing that his physicians had failed to disclose information material to his treatment decision, with the result that his consent was not informed. The upshot, they claimed, was that he undertook treatment he would otherwise have declined and, harboring false hope, never settled his business affairs. Consequently, at his death his business failed, to his family's detriment.

The issue on appeal was the adequacy of the trial court's jury instructions, which spoke only generally of physician duties to provide material information and gave no guidance on whether mortality statistics were material. What most clearly reveals the court's continuing ambivalence toward disrupting physician custom by requiring disclosure, however, is the court's treatment of the physicians' defense.

Dr. Avedon, the chief oncologist, defended withholding mortality rates, even

14. *Schloendorff v. Soc'y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914).

15. *Salgo v. Leland Stanford Jr. Univ. Bd. of Trs.*, 317 P.2d 170 (Cal. Dist. Ct. App. 1957); see also KATZ, *THE SILENT WORLD*, *supra* note 1, at 60–65.

16. *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972).

17. KATZ, *THE SILENT WORLD*, *supra* note 1, at 71–80 (commenting on *Canterbury*'s ambivalent approach to the therapeutic exception, among other issues).

18. See 1 BARRY R. FURROW ET AL., *HEALTH LAW* 413 & n.7 (1995) (noting that over twenty-five states adopted a standard for disclosure based on physician custom despite *Canterbury*'s rejection of that standard); KATZ, *THE SILENT WORLD*, *supra* note 1, at 81–82.

19. 858 P.2d 598 (Cal. 1993).

20. *Id.* at 600.

though Mr. Arato had indicated on an office intake questionnaire that he wanted to be told “the truth.”<sup>21</sup> The physician argued that he did not want to deprive his cancer patients of a hope of cure, no matter how misplaced that hope might be. He did not want to give his patients “a cold shower.”<sup>22</sup> Further, the physician claimed that statistical life expectancy data described the experience of aggregates. He claimed that those group statistics had little predictive value for the individual patient. Dr. Avedon argued that discovering Mr. Arato’s cancer early, in the course of an unrelated surgery, plus the location of the tumor on the distal portion of the pancreas, suggested a better prognosis than the statistics indicated.<sup>23</sup>

The physician failed to address the fact that statistics are always about aggregates and serve only as a starting point for discussion. The physician has to help the patient interpret the persuasiveness of the statistics (depending on how recent the studies are, sample size, whether multiple studies have produced numbers that agree, and other factors). Then the doctor has to address whether the patient’s case suggests better or worse odds than the aggregates studied. Statistics are the crucial starting point for this conversation, not the end point.

The court nonetheless bought the physician’s defense hook, line, and sinker. Without questioning already settled law that the physician had to disclose all material information to obtain effective consent, the court proclaimed its commitment to avoiding the “extremes of ‘patient sovereignty’ and ‘medical paternalism.’”<sup>24</sup> Yet the court then embraced every paternalistic argument offered by the defense. “Statistical morbidity values derived from the experience of population groups are inherently unreliable.”<sup>25</sup> They “offer little assurance regarding the fate of the individual patient.”<sup>26</sup> Treating these statistics as “conclusive” suggests “medical abdication of the patient’s well-being.”<sup>27</sup>

As always, the court’s language is revealing. It suggests that the physician should convey what is reliable and assuring, not something as probabilistic and unsettling as survival statistics. Further, the physician should serve the patient’s well-being as the physician conceives it, not a particular patient’s express wish for the truth.

This is a throwback to old-style, paternalistic practice. It ignores the fact that part of a doctor’s job is giving bad news. Surely, that is part of an oncologist’s

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21. *Id.*

22. *Id.* at 601.

23. *Id.*

24. *Id.* at 606.

25. *Arato v. Avedon*, 858 P.2d 598, 607 (Cal. 1993).

26. *Id.*

27. *Id.*

job, especially if he is then seeking informed consent to burdensome treatment, as in this case. Physicians need training and may need help to do this well, but retreating from the challenge is lapsing back into the Hippocratic silence that Katz decries. There is no doubt that sustaining a patient's hope and ability to function in the face of bad news is a challenge, but a vast literature now speaks to the skill of doctors and other health professionals in doing just that.<sup>28</sup> Further, many studies have documented the public's wish for honest information, even if the news is dire.<sup>29</sup> Without that information, it is hard to see how terminal patients could make medical decisions, cope, make peace with family and friends, and settle their affairs. Indeed, this is precisely what Mr. Arato's family complained of in their suit, namely that withholding the facts about how bad his prognosis was deprived Mr. Arato of the chance to do those things.

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28. See, e.g., J.T. Ptacek & Tara L. Eberhardt, *Breaking Bad News: A Review of the Literature*, 276 JAMA 496 (1996); Michael W. Rabow & Stephen J. McPhee, *Beyond Breaking Bad News: How To Help Patients Who Suffer*, 171 W.J. MED. 260 (1999); Ronald P. Strauss et al., *Physicians and the Communication of "Bad News": Parent Experiences of Being Informed of Their Child's Cleft Lip and/or Palate*, 96 PEDIATRICS 82 (1995). A substantial literature offers improved methods of disclosing bad news to patients. See, e.g., Walter F. Baile et al., *SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer*, 5 ONCOLOGIST 302 (2000); Afaf Girgis & Rob W. Sanson-Fisher, *Breaking Bad News 1: Current Best Advice for Clinicians*, 24 J. BEHAV. MED. 53 (1998) [hereinafter Girgis & Sanson-Fisher, *Current Best Advice*]; Afaf Girgis & Rob W. Sanson-Fisher, *Breaking Bad News: Consensus Guidelines for Medical Practitioners*, 13 J. CLINICAL ONCOLOGY 2449 (1995).

29. See, e.g., V. Jenkins et al., *Information Needs of Patients with Cancer: Results from a Large Study in UK Cancer Centres*, 84 BRIT. J. CANCER 48, 49 (2001) (reporting that 87% of 2331 patients surveyed said that they would prefer "to have as much information as possible, both good and bad"); H. Miyata et al., *Disclosure Preferences Regarding Cancer Diagnosis and Prognosis: To Tell or Not To Tell?*, 31 J. MED. ETHICS 447, 449 (2005) (finding that 86.1% of cancer patients surveyed in Japan indicated they desired full disclosure); Martin H.N. Tattersall et al., *The Take-Home Message: Patients Prefer Consultation Audiotapes to Summary Letters*, 12 J. CLINICAL ONCOLOGY 1305, 1307 (reporting that 171 of 182 cancer patients enrolled in the study "wanted all information, good or bad"); see also L.J. Fallowfield, *Truth May Hurt But Deceit Hurts More: Communication in Palliative Care*, 16 PALLIATIVE MED. 297, 302 (2002) ("There is little or no convincing evidence supporting the contention that terminally ill patients who have not been told the truth of their situation die happily in blissful ignorance."); Girgis & Sanson-Fisher, *Current Best Advice*, *supra* note 28, at 53 (discussing the increase over the last forty years in the number of patients who want to know about their diagnosis). For a highly influential study of patients' preferences see generally Louis Harris et al., *Views of Informed Consent and Decisionmaking: Parallel Surveys of Physicians and the Public*, in 2 PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMEDICAL & BEHAVIORAL RESEARCH, MAKING HEALTH CARE DECISIONS: THE ETHICAL AND LEGAL IMPLICATIONS OF INFORMED CONSENT IN THE PATIENT-PRACTITIONER RELATIONSHIP 17 (1982).

Moreover, communicating the facts of Mr. Arato's prognosis virtually required that his doctors articulate the survival statistics for Mr. Arato's type of cancer and the expected impact of the chemotherapy/radiation regimen offered. The fact that less than five percent of patients with pancreatic cancer survived at least two years and that the regimen would at best give him only a few extra months was material.

On the physician's side of the table, no oncologist would seriously consider treating cancer patients without careful attention to survival statistics. Such statistics are basic to oncology decisions.<sup>30</sup> All of medicine is moving toward evidence-based practice and increased attention to data in an effort to improve care.<sup>31</sup> Rejecting the statistics also means rejecting the trend toward evidence-based medicine, a trend overwhelmingly seen as essential to eliminating inappropriate variation in practice patterns and to improving care. To be sure, statistics are based on the experience of population groups, but that is precisely what makes those statistics reliable. One cannot practice competent oncology without understanding the empirical literature and interpreting the statistics. Determining the implications of those statistics for an individual case is a further interpretive act. The physician must compare the characteristics of the sample population with those of the patient. The aggregate statistics are where the physician begins. To suggest that physicians should avoid this process and regard the statistics as "inherently unreliable" is to argue for malpractice.

Perhaps, though, Dr. Avedon was not arguing that statistics were irrelevant to his practice, but that sharing statistics with his patient would have been a mistake because the patient would not have had the ability to understand the numbers. Even this narrower version of the argument is hard to defend, though. Patients are given statistical information all the time, be it about their chances to conceive a child, their genetics, or the chances a drug will have side effects.<sup>32</sup>

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30. See, e.g., Aman Buzdar & Cynthia Macahilig, *How Rapidly Do Oncologists Respond to Clinical Trial Data?*, 10 *ONCOLOGIST* 15, 15–16 (2005); Monika K. Krzyzanowska et al., *Factors Associated with Failure To Publish Large Randomized Trials Presented at an Oncology Meeting*, 290 *JAMA* 495, 495 (2003) ("Large randomized controlled trials are the criterion standard upon which most treatment decisions are made . . .").

31. See, e.g., Leah L. Albers, "Evidence" and Midwifery Practice, 46 *J. MIDWIFERY & WOMEN'S HEALTH* 130 (2001) (midwifery); Mohit Bhandari et al., *From Eminence-Based Practice to Evidence-Based Practice: A Paradigm Shift*, *MINN. MED.*, Apr. 2004, at 51 (orthopedics); Donna Hallas & Bernadette Mazurek Melnyk, *Evidence-Based Practice: The Paradigm Shift*, *J. PEDIATRIC HEALTH CARE*, Jan.-Feb. 2003, at 46 (pediatrics); David L. Sackett & William M.C. Rosenburg, *The Need for Evidence-Based Medicine*, 88 *J. ROYAL SOC'Y MED.* 620 (1995) (general medicine); Annette Sterr, *Training-Based Interventions in Motor Rehabilitation After Stroke: Theoretical and Clinical Considerations*, 15 *BEHAV. NEUROLOGY* 55 (2004) (neurology).

32. See, e.g., Andria Dyck et al., *Pharmacists' Discussions of Medication Side Effects: A*

Certainly, patients may need help to interpret the statistics properly. Genetic counselors, for example, train to do exactly that. Oncologists, too, need to know how to communicate such information. For lack of the statistical data, how can a patient know whether generalities such as “the prognosis is poor” mean that 40%, 20%, or 5% of people with the same kind of cancer survive two years? And knowing which number applies may be highly material to the patient’s treatment decision.<sup>33</sup>

Thus, we see in *Arato* judicial as well as physician resistance to Katz’s revolution. Faced with a rising and salutary empiricism, with statistical analyses and meta-analyses,<sup>34</sup> the court and physicians seek refuge in silence. Katz teaches

*Descriptive Study*, 56 PATIENT EDUC. & COUNSELING 21, 22 (2005) (noting that empirical evidence shows that patients prefer numerical (e.g., 0.1%, 1 out of 1000) rather than verbal (e.g., rare, infrequent) frequency descriptors in learning of risks associated with medications); Mercy Y. Laurino et al., *Genetic Evaluation and Counseling of Couples with Recurrent Miscarriage: Recommendations of the National Society of Genetic Counselors*, 14 J. GENETIC COUNSELING 165, 178 (2005); Practice Comm., Am. Soc’y Reprod. Med., *Elements To Be Considered in Obtaining Informed Consent for ART*, 82 FERTILITY & STERILITY S202, S202 (2004) (recommending information to be disclosed to patients before utilizing assisted reproductive technologies); Practice Comm., Am. Soc’y Reprod. Med., *Information on Commonly Asked Questions About Genetic Evaluation and Counseling for Infertile Couples*, 82 FERTILITY & STERILITY S97, S100 (2004) (providing statistical data about genetic diseases that ought to be shared with patients in preconception counseling).

33. In fact, a considerable literature exists on how to properly convey statistical data to patients and how to frame those statistics. See, e.g., Sidney T. Bogurdus, Jr. et al., *Perils, Pitfalls, and Possibilities in Talking About Medical Risk*, 281 JAMA 1037 (1999); Dyck et al., *supra* note 32, at 22; Ronald M. Epstein et al., *Communicating Evidence for Participatory Decision Making*, 291 JAMA 2359 (2004); Hitinder Singh Gurm & David G. Litaker, *Framing Procedural Risks to Patients: Is 99% Safe the Same as a Risk of 1 in 100?*, 75 ACAD. MED. 840 (2000); see also, e.g., Amos Tversky & Daniel Kahneman, *The Framing of Decisions and the Psychology of Choice*, 211 SCIENCE 453 (1981) (arguing that changes in how information is presented to a decision-maker can significantly alter the decision made). For example, empirical evidence shows that patients are more willing to undergo a particular procedure if told that 99% of previous patients did not have any complications than if told that complications are seen in 1 out of 100 people who underwent the procedure. Gurm & Litaker, *supra*, at 841. Thus, the pertinent question for physicians is not whether to give patients statistical information, but how.

34. See generally Ethan M. Balk et al., *Correlation of Quality Measures with Estimates of Treatment Effect in Meta-analyses of Randomized Controlled Trials*, 287 JAMA 2973 (2002) (stating that a pre-planned meta-analysis of individual trials with deliberately introduced variables may maximize the effectiveness of results from randomized trials); Jesse A. Berlin & Graham A. Colditz, *The Role of Meta-analysis in the Regulatory Process for Foods, Drugs, and Devices*, 281 JAMA 830 (1999) (analyzing the effectiveness of meta-analyses to test the reliability of randomized trials).

us this is more than lagging behind, more than an anachronism. It is resistance, anxiety, and reaction. Sadly, this response is not confined to those facing the rough and tumble of the real world. We see it penetrating the academy as well.

Carl Schneider's book, *The Practice of Autonomy*,<sup>35</sup> is an example. He takes issue with Katz and others, accusing them of a hyper-rationalistic commitment to patient autonomy.<sup>36</sup> Schneider claims that this argument for autonomy is at odds with what many patients want: the doctor making treatment decisions.

Schneider's accusation of hyper-rationality is especially peculiar applied to Katz's work. Given Katz's psychoanalytic perspective, it is no surprise to see his insights built on acknowledging and accepting the *non-rational*. Indeed, Katz is a master at describing the child-like regression and surrender that illness invites. Thus, it is puzzling to see Schneider claim that "Katz reproves patients who shirk decisions."<sup>37</sup> In fact, Katz finds the child-like desire to flee from making decisions and to surrender to the doctor part of being a patient: "Since illness is a situation of neediness and fear, it stimulates wishes to surrender to authority and fantasies about omnipotent caretakers to whom one must yield."<sup>38</sup>

Schneider's book turns on a chapter in which he reviews empirical studies of what information patients want and what decisional role.<sup>39</sup> He points to a number of studies in which patients say they want the doctor to decide. However, the studies he cites cover a wide range of decisional circumstances. They range from studies asking whether the respondent would like her physician to pick which drug she is prescribed for hypertension to studies asking whether the respondent would want the physician to decide if she received life-sustaining treatment. Yet people may well feel that it is fine for the doctor to make the former choice but unacceptable for the doctor to make the latter. Once the decision has been made to take some kind of medication for hypertension, choosing which drug may seem to be a relatively inconsequential and delegable decision. It may even seem a rather technical decision involving drug comparisons the doctor knows best. On the other hand, deciding whether to forgo life-sustaining treatment has life-or-death consequences and clearly implicates the patient's subjective values—would she rather suffer the burden of artificial ventilation to try to live longer, or has she had enough? Thus, lumping together these decisional scenarios confuses the picture.

Further, Schneider mixes tiny studies that would not be included in any

35. CARL E. SCHNEIDER, *THE PRACTICE OF AUTONOMY: PATIENTS, DOCTORS, AND MEDICAL DECISIONS* (1998).

36. *Id.* at 11–17, 30–31, 35.

37. *Id.* at 12.

38. KATZ, *THE SILENT WORLD*, *supra* note 1, at 211–12.

39. SCHNEIDER, *supra* note 35, at 35–46.

rigorous meta-analysis with more powerful studies that may actually mean something. Missing is a real meta-analysis that would allow Schneider to aggregate and interpret studies. Only that would allow him to come up with a persuasive picture of what the studies show about preferences for information and decisional roles.

The deeper problem, however, is that Schneider misses Katz's point. Sure, a lot of patients show up in a doctor's office (or, to follow the methodology of many of these surveys, imagine showing up) and say they want the doctor to take care of them, for the doctor to decide. That does not answer the question, though, of what information the patient wants and what decisional role. Instead, it sets up the question. It is precisely at this starting point that Katz calls for conversation, candor, and connection. Indeed, the physician may have to educate the patient about her entitlement to information and decisional authority. The real question is what does the patient want then, informed of her options and authority. Schneider is giving up on patients too soon, before they even reliably know that they can function as adults in the doctor-patient relationship without risking abandonment by or anger from their physician.

What do we make of all this resistance, then, from the clinic, the courts, and the academy? Professor Katz has heard it all before—the revolution is doomed. Commentators have complained that Katz's vision asks too much of the physician, that it is unrealistic. They argue that there is not enough time for doctor and patient to explore values and options as Katz envisions.<sup>40</sup> They note that the physician and patient in this county often meet as strangers from different worlds, not one.<sup>41</sup> They object that the physician increasingly serves her organization, not the patient, anyway.<sup>42</sup>

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40. See SCHNEIDER, *supra* note 35, at 145–46; see also Adrian Edwards & Glyn Elwyn, *Involving Patients in Decision Making and Communicating Risk*, 10 J. EVALUATION CLINICAL PRAC. 431, 434 (2004) (finding that while many doctors want to involve patients in decision-making, the doctors surveyed agreed that lack of time remained an obstacle).

41. See E. HAAVI MORREIM, *BALANCING ACT: THE NEW MEDICAL ETHICS OF MEDICINE'S NEW ECONOMICS* 149–50 (1991) (explaining that patients and physicians do not conceive of risks in the same way); SCHNEIDER, *supra* note 35, at 146–47; see also Renee R. Anspach, *Prognostic Conflict in Life-and-Death Decisions: The Organization as an Ecology of Knowledge*, 28 J. HEALTH & SOC. BEHAV. 215, 230 (1987) (“As [patients] become increasingly reliant upon physicians to interpret an increasingly esoteric knowledge, they run the risk of becoming peripheral to life-and-death decisions and a truly informed consent becomes difficult to attain.”).

42. See MORREIM, *supra* note 41, at 100 (arguing that physicians should not “commandeer others’ money and property just because a given patient has need of it”); SCHNEIDER, *supra* note 35, at 186–206; see also MARC A. RODWIN, *MEDICINE, MONEY, AND MORALS: PHYSICIANS’ CONFLICTS OF INTERESTS* 162 (1993) (finding that when HMOs pay physicians to limit the use of resources, doctors are more likely to limit medical care to increase their income); Anspach, *supra* note 41, at



It would be easy to be discouraged. The time pressures, care between strangers, and pressures on physicians to serve the organization rather than patient are real. Yet in the face of all of that, what is remarkable is how far the revolution has actually come.

Yes, SUPPORT shows physician resistance to doing as patients wish at the end of life. But this is against the background of profound change in how we look at such decisions. The last few decades have seen tremendous agreement that decision-making should be a shared process but that patient preferences should rule.<sup>43</sup> And that agreement prevails even when the predicted consequence of honoring the patient's wish is her death.<sup>44</sup>

Yes, physician failure to listen and establish a positive therapeutic relationship is worse when the patient is a person of color, a woman, or both. But there is tremendous agreement throughout the medical profession—from the clinic to the Institute of Medicine—that this problem is serious and must be addressed.<sup>45</sup> And there are promising ideas for enlisting whole communities as well as individual doctors and patients to address it.<sup>46</sup>

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229 (suggesting that physicians are structurally and organizationally disengaged from their patients); Margaret Urban Walker, *Keeping Moral Space Open*, HASTINGS CENTER REP. Mar.-Apr. 1993, at 33 (discussing the role of the clinical ethicist in protecting the patient from medical bureaucracy).

43. See TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 77–80 (5th ed. 2001); Eric J. Cassell, *Consent or Obedience? Power and Authority in Medicine*, 352 NEW ENG. J. MED. 328, 329 (2005).

44. See, e.g., ALAN MEISEL & KATHY L. CERMINARA, *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING* §§ 2.01–2.05 (3d ed. 2005) (discussing *In re Quinlan*, 355 A.2d 647 (N.J. 1976), *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990), and their progeny); Lewis M. Cohen, *Practical Considerations in Dialysis Withdrawal: "To Have That Option Is a Blessing"*, 289 JAMA 2113, 2114 (2003).

45. See, e.g., INST. OF MED., *supra* note 8, at 160–179, 552–93; ALEXANDRA DUNDAS TODD, *INTIMATE ADVERSARIES: CULTURAL CONFLICT BETWEEN DOCTORS AND WOMEN PATIENTS* 77 (1989) (observing that “the darker a woman’s skin and/or the lower her place on the economic scale, the poorer the care and efforts at explanation she received”); Anita L. Stewart et al., *Interpersonal Processes of Care in Diverse Populations*, 77 MILBANK Q. 305 (1999) (analyzing how the social-psychological aspects of the patient-physician relationship affect the quality of care in diverse populations); see also sources cited *supra* note 8 (describing further research showing worse therapeutic relationships between doctors and minorities and women).

46. See, e.g., INST. OF MED., *supra* note 8, at 580 (outlining strategies for improving communication skills of physicians); Timothy S. Carey et al., *Developing Effective Interuniversity Partnerships and Community-Based Research to Address Health Disparities*, 80 ACAD. MED. 1039 (2005) (suggesting that universities work with communities to promote racial understanding in research medicine); see also, e.g., Janice C. Blanchard, *Racial and Ethnic Disparities in Health: An Emergency Medicine Perspective*, 10 ACAD. EMERGENCY MED. 1289, 1291 (2003) (providing

Yes, the court in *Arato* falls apart like a terrified patient faced with the dire statistics, the death sentence of pancreatic cancer. But at least the judges hold true to *Cobbs*,<sup>47</sup> their own precedent, maintaining that the physician should disclose everything material. And though the court suggests that it cannot face these statistics and refuses to mandate a charge requiring the jury to face them either, the court allows the jury to consider whether the statistics were material, and if so, find the physician liable for failure to inform the patient adequately.

Yes, Schneider is among those arguing that we have gone too far in pursuing patient autonomy, that many patients do not want to decide for themselves. But even Schneider reads the empirical studies to say that patients do want the relevant information.<sup>48</sup> And beyond that, he sees a “telling pattern[.]” in the studies suggesting that change is coming in what decisional role patients prefer.<sup>49</sup> The data show that younger patients are more likely than older ones to prefer participation in medical decisions or to prefer actually making those decisions themselves.<sup>50</sup>

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suggestions for improving patient-physician relationships); Elizabeth Harrison & Suzanne M. Falco, *Health Disparity and the Nurse Advocate*, 28 *ADVANCES NURSING SCI.* 252, 262–63 (2005) (explaining that nursing interventions at the community level may assist in the identification of values to improve the patient-physician relationship); cf. Neal Dickert & Jeremy Sugarman, *Ethical Goals of Community Consultation in Research*, 95 *AM. J. PUB. HEALTH* 1123 (2005) (discussing how to involve communities in health research); Alice K. Page, *Ethical Issues in International Biomedical Research: An Overview*, 37 *J. HEALTH L.* 629, 645–47 (2004) (“By ensuring that the role of the community goes beyond the simple participation of its individual members as research subjects, community consultation is designed to respect the culture, values, and dignity of the community and to obtain full understanding and acceptance of the research project.”).

47. *Cobbs v. Grant*, 502 P.2d 1 (Cal. 1972).

48. SCHNEIDER, *supra* note 35, at 36.

49. *Id.* at 41.

50. For example, a study of more than 2750 people in 2002 found that patients below age forty-five desired more participation in medical decision-making than patients above forty-five. Wendy Levinson et al., *Not All Patients Want To Participate in Decision Making*, 20 *J. GEN. INTERNAL MED.* 531, 533 (2005). Schneider recognizes this pattern but says “it is unclear whether this [empirical evidence] represents a change in the direction of social attitudes or a stable difference between the young and the old.” SCHNEIDER, *supra* note 35, at 33. The authors of the 2002 study struggled with this same question. See Levinson et al., *supra*, at 534. They speculated, however, that as the current, information-seeking generation ages, future studies may find the older population favoring more participation in medical decisions. See *id.* The empirical evidence may support a combination of both hypotheses: Severe illness in later life may incline older individuals to defer to a physician’s best judgment, but a generation accustomed to making decisions about their health care is unlikely to surrender that autonomy readily as they age. In any case, numerous studies show that younger patients want more participation in health care decisions than older patients. See, e.g., Mark A. Davis et al., *Impact of Patient Acuity on Preference for Information and*

Would this gut-wrenching struggle, this ferocious ambivalence, surprise Dr. Katz? I think not. Any less resistance would suggest we had missed the mark, that we were failing to seek fundamental change. After all, this is a revolution. Profound resistance comes with the territory.

So where does this unfinished revolution go from here? Alexander Capron urges in his forward to the new edition of *Silent World* that we look to the next generation of physicians to realize Jay's vision.<sup>51</sup> Capron suggest that nothing short of generational change will bring the needed transformation. But I think he underestimates the challenge. It will take more.

We have to await not just the next generation of physicians, but the next generation of patients. We have to look to our children, raised with a different set of expectations about their body, their decisions, their illness, and their death. The doctor-patient relationship is a two-way street.

There is reason to be optimistic about change among both patients and doctors. The data showing younger patients preferring a more active decisional role in their care jibe with changes we see around us, changes in families, in schools, on television, and on the Internet. We see greater candor with children and adolescents about their bodies and medical care. We see older children better able than many of their parents to navigate the Web and find out about illness, disability, medical options, and peer experiences. We see efforts to encourage children to see their bodies as their own, and refuse unwanted contact.<sup>52</sup>

Among physicians, we see greater efforts in medical school and beyond to

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*Autonomy in Decision Making*, 6 ACAD. EMERGENCY MED. 781, 784 (1999) (finding age a significant factor in the desire of emergency department patients to participate in medical decision-making); Glenn Salkeld et al., *A Matter of Trust: Patient's Views on Decision-Making in Colorectal Cancer*, 7 HEALTH EXPECTATIONS 104, 112 (2004) (finding similar results in an Australian cancer study); Suzanne C. Thompson et al., *Preferences for Involvement in Medical Decision-Making: Situational and Demographic Influences*, 22 PATIENT EDUC. & COUNSELING 133, 137-38 (1993) (finding that younger adults wanted more involvement, regardless of the severity of the medical condition).

51. Alexander Morgan Capron, *Foreword to KATZ, THE SILENT WORLD*, *supra* note 1, at xxxii.

52. Evidence of the efforts to encourage children and adolescents to make their own decisions about their bodies includes Jennifer M. Cohn et al., *Adolescent Decisional Autonomy Regarding Participation in an Emergency Department Youth Violence Interview*, 5 AM. J. BIOETHICS 70, 70-74 (2005); Kimberly M. Mutcherson, *Whose Body Is It Anyway?: An Updated Model of Healthcare Decision-Making Rights for Adolescents*, 14 CORNELL J.L. & PUB. POL'Y 251 (2005); and John S. Santelli et al., *Guidelines for Adolescent Health Research: A Position Paper of the Society for Adolescent Medicine*, 33 J. ADOLESCENT HEALTH 396 (2003). *See also* Ingrid Runeson et al., *Professionals' Perceptions of Children's Participation in Decision Making in Healthcare*, 10 J. CLINICAL NURSING 70, 77 (2001) (studying how medical professionals perceive children's expressions of autonomy).

teach them to talk with patients and to listen. Explicit training in medical ethics or bioethics has penetrated the medical school curriculum and become part of residency. Physicians in practice are less and less surprised to see patients arrive for an office visit having researched their illness and toting Internet print-outs.<sup>53</sup>

Of course, generational change in doctors and patients may not be enough. *Arato* reveals persisting physician paternalism as well as judicial sympathy for that approach. We may need to await the next generation of judges and legislators as well.

Yet change is afoot. Katz analyzes the fitful start to this revolution. Over forty years elapsed between Justice Cardozo's 1914 announcement of a patient's "right to determine what shall be done with his own body"<sup>54</sup> and judicial development of the requirement of informed consent, starting in 1957. Has the revolution progressed in the nearly fifty years since then?

I am arguing that it has. Let me illustrate with the personal.

It is 1958, one year after the doctrine of informed consent fitfully erupted in *Salgo*,<sup>55</sup> as Katz chronicles. I am five years old, dressed in my best smock dress, told we are going to visit my grandparents. Instead, we pull up to a huge grey building I have never seen. My parents take me inside. I am panicking. They place me on a bare examining table in a cavernous room, empty save for a man and a canister. The stranger forces a mask on my face. My parents wrestle me onto my back. I am being murdered. I fight for my life. I lose consciousness. The total silence, the terror, the utter conviction I was being killed haunt me still. It is surely part of why I do this work.

Flash forward, through a series of informed consent cases, including *Natanson*,<sup>56</sup> *Canterbury*,<sup>57</sup> *Cobbs*,<sup>58</sup> and *Arato*.<sup>59</sup> I am a mother of twins, now five

53. See, e.g., Jeffrey P. Lake, *Internet Use by Colorectal Surgery Patients: A Surgeon's Tool for Education and Marketing*, 70 AM. SURGEON 553, 556 (2004) (45.1% of 298 surveys returned in a 2004 study indicated that patients used the Internet to research their condition prior to their first visit to the clinic); Sanjay K. Pandey et al., *Women's Health and the Internet: Understanding Emerging Trends and Implications*, 56 SOC. SCI. & MED. 179, 181–82 (2003) (analyzing the increase in women's use of the Internet to find health information); Matthew R.G. Taylor et al., *Use of the Internet by Patients and Their Families To Obtain Genetics-Related Information*, 76 MAYO CLINIC PROC. 772 (2001) (finding in a 2001 study that 47% of 155 respondents referred to a genetics clinic from their general practitioner acknowledged using the Internet to research their genetic condition before their clinic visit).

54. *Schloendorff v. Soc'y N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914).

55. *Salgo v. Leland Stanford Jr. Univ. Bd. of Trs.*, 317 P.2d 170 (Cal. Ct. App. 1957).

56. *Natanson v. Klein*, 350 P.2d 1093 (Kan. 1960).

57. *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972).

58. *Cobbs v. Grant*, 502 P.2d 1 (Cal. 1972).

59. *Arato v. Avedon*, 858 P.2d 598 (Cal. 1993).

years old themselves. Both have needed surgery. In each case, we tell our sons everything, as best we can. We play with dolls and doctor kits, go to see the hospital ahead of time, and read books together. Why? Not just because my husband and I are good guys, but because the doctors, and nurses, and social workers told us to do so. After almost fifty years, something has changed, some combination of medical personnel, practice, and institution. Perhaps even parenting has changed.

And who do these children become? Who is this next generation of patients, growing up mid-revolution?

Not long ago one of my sons was ill. He needed blood to be drawn from a vein at the hospital lab. He refused. He would not get in the car. As his anxiety mounted, he defended himself. He struck karate poses and waved a plastic sword at us. At the height of this he screamed, "It's *my* body!"

That stopped me in my tracks. My son was right. He was not making the choice we wanted, but he was right. My husband, exasperated, hissed at me, "You taught him that." And so I had. But not just me—we had both taught him that, as had his teachers, and his books. It is your body. Say no.

Now, I can imagine emergencies in which we might have to wrestle my child to the ground to get urgent medical care. But, in truth, this was not one of those times. Nothing irrevocable would happen if we failed to reach the lab that day. So we did not go. Instead, we went to see the pediatrician in his office the following day. And what finally persuaded my son to go the lab was nothing we did. It was conversation with his doctor. Our son sat on the examining table eye-to-eye with his pediatrician. Even at five years old, he listened to his doctor explaining why he needed blood drawn and what his choices were. My son decided: "OK. Let's go to the hospital, Mom." That is how powerful doctor-patient dialogue can be.

Fifty years ago, would the child's cry that "it's my body" have been met with respect or with muscle? Would the physician have stood in dialogue with his young patient? Would the child have tasted control, conversation, and choice? Would he have glimpsed something like rights?<sup>60</sup>

I doubt it. There are deep changes afoot. Jay Katz's vision calls for no less—profound changes, not just in doctoring, but in caring for our children, our families, ourselves. It is a revolution. Unfinished, yes, but in motion.

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60. See generally NANCY E. WALKER ET AL., CHILDREN'S RIGHTS IN THE UNITED STATES: IN SEARCH OF A NATIONAL POLICY 144 (1999) (discussing the role of parents in making medical decisions for children); Martha Minow, *What Ever Happened to Children's Rights?*, 80 MINN. L. REV. 267, 268–80 (1995) (outlining the development of children's rights from the 1960s to the 1990s).