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AUTONOMY AND RISK TAKING

Research with Human Subjects as a Paradigm in Teaching

Larry I. Palmer

As a university administrator, I worry about the form and substance of undergraduate education and about ways to encourage interdisciplinary perspectives on problems in a research university dominated by particular specialized disciplines. I also continue to teach a seminar in Cornell’s Biology & Society Program for undergraduates and to assist others in teaching a course called “Medical Humanities” for second-year medical students. In the course of these administrative and teaching activities, I find myself returning to Jay Katz’s Experimentation with Human Beings—a model for teaching and as a perspective for institutional learning and change—as a model for professional action.

Jay Katz’s approach to research with human subjects provides an excellent framework for analyzing the nature of teaching not simply in professional or continuing education programs in law, medicine, or social work, but in undergraduate programs as well. In my view, changing the ways in which universities help students to learn at all levels can be analyzed through the process of reflection, action, and evaluation developed in Katz’s seminal work on human experimentation and most recently expounded in his suggested reforms of professional medical education in The Silent World of Doctor and Patient. For Jay Katz, the scholar who guided me to the realization that teaching and administering within the university at all levels is essentially a problem in human research, I offer this tribute.

First, through reference to his analytical perspectives and some of his materials that I have used in courses and seminars in law school, medical college, and undergraduate college settings over the past fifteen years, I will illustrate why Katz’s perspective is essential to understanding the fundamental issues in law and medicine. Second, to provide a perspective on the current crisis in undergraduate education, I will outline the concept of “knowledge processes,” derived in part from Katz’s work and in part from my own teaching. This so-called crisis is indicative of a basic confusion about the purposes of higher education and research generally, not just research with human subjects in our society. I will end with a story—a personal story about my own teaching—that is a fitting tribute to Jay Katz, the scholar who always teaches.

Science, Medicine, and the Law

As basic social institutions in modern society, science, medicine, and law are important sources of authority for resolving the ethical dilemmas of our time. Each of these institutions creates metaphors that guide often conflicting decision-making processes. Medicine, for instance, whose practitioners epitomize the notion of the “helping professional,” suggests for many the highest ideals of healing. Law evokes multiple images of rights, order, and justice. Science, to modern men and women, elicits an almost religious view of rationality. In teaching law and medicine to undergraduates, law students, and medical students, I have found Katz’s work to be an important resource for helping them sort out the various meanings of authority within science, medicine, and law and think about the interrelationships in ways that are beneficial both to their future clients and to society. I suggest that it is not what physicians or lawyers do that is the starting point for analysis of the issues of law and medicine; rather, it is an institutional view of science which provides the framework.

Science is an important social institution because it responds to an important human need, the quest for knowledge. Whether it be the curiosity of the child who drops the feeding dish to see what happens or Newton’s wonder at a falling object moving in an arc, this quest for knowledge about the world seems inherent in man. The modern scientific enterprise is the institutional man-
Ifestation of this basic human need. We often confuse what scientifically-trained individuals do with the institution of science itself. This confusion of the institution of science with the practice of professionals often leads us to ignore the pervasive influence of science upon the way we view the world. We expect, for instance, managers in business enterprises to be professional in the sense that they supposedly rely upon the "science of management," which itself may be based on mechanistic views of organizations. Once it is clear that the paradigms of science are the backbone of modern professionalism, many of the issues in law and medicine can be seen as recurrently inadequate human attempts of physicians, lawyers, judges, and legislators to apply scientific notions of expertise to deal with disease, decay, and death. Thus, much of my teaching about law and medicine is an attempt to help students develop a way of thinking about professional ethics in the context of science, medicine, and law.

Katz's process approach to human experimentation has always helped me beat the pedagogical demon that seems to possess modern students at all stages of their educational development. This demon, in my view, assumes that ethical reasoning for the real world is simply a self-generated ethical theory, detached from human beings and the wider social context.

My approach to professional ethics in medicine is built on the assumption that professionals always operate in an organizational and institutional context. This approach is best exemplified by "The Jewish Chronic Disease Hospital Case," the introductory case in Experimentation with Human Beings. This case, involving two physicians who conducted experiments using live cancer cells on debilitated patients, remains the paradigm for teaching students about physicians' roles under modern conditions. The case is so rich with paradoxes about professional ambitions and professional service, organizational politics at both the staff and board of director levels, and the relationship of courts and administrative agencies to the drama, that students never leave this case with the unequivocal feeling that the experiments should be condemned. Rather they see that the forces that prompted the experiments to be conducted in the first place require thorough analysis in order that appropriate controls may be imposed to prevent repetition of a like experiment in the future.

For two reasons, the role of the physician is the fundamental issue for a teacher of law and medicine. First, any type of legal intervention into medical decisions must confront the typical layperson's response to the physician as a revered and esteemed member of the community. He or she is viewed not simply as healer but as a modern day "high priest." Second, the problems that law must confront in modern medicine do not in fact arise in the context of the physician practicing the art of healing, but rather in his or her applying the techniques of science to the problems of disease and decay. Katz's work captures these two essential features of the physician's role in modern society: As the practitioners of medicine have relied upon science for their authority, the lay public has assumed that the authority of the physician lies in his art of healing.

In trying to resolve the conflict between a rapidly emerging biomedical capacity to treat disease and a patient population imbued with notions of healing, we have relied upon legalistic notions of consent. "Consent" has become the new source of authority for a confused public and the beleaguered professionals. Katz, beginning in Experimentation with Human Beings, and most recently with The Silent World of Doctor and Patient, challenged the conventional wisdom of our times that issues of consent will resolve most ethical dilemmas. In his early work Katz dared to ask three fundamental questions: What are the functions of consent? What limitations are inherent in informed consent? What limitations should be imposed on informed consent? While these questions are in a sense unanswerable, they help the teacher of medical malpractice cases to be wary of assuming that a legal requirement of consent resolves the underlying issue of legitimate use of authority.

Katz, addressing these issues in expository form in The Silent World of Doctor and Patient, demonstrates why law's reliance on informed consent is an illusionary "fairy tale." He does not argue that consent is never possible, but rather that consent that respects the autonomy of patients requires a radically new conceptualization of the physician's role.

According to Katz, modern physicians know more about what they do not know about the effectiveness of treatments than did their counterparts only fifty years ago. Thanks to the advance of scientific knowledge, the modern physician now knows why some treatments work for some patients while others do not. Ironically, the growth of scientific knowledge in medical practice has in fact increased the degree of uncertainty under which physicians must operate. Katz argues that physicians must learn how to share with the patient what is known and unknown about a proposed treatment are in fact more scientific in their discussion of risks with patients. Too many practitioners' attempts to deal with the issues of uncertainty in professional practice fail to distinguish between law, medicine, and science as sources of authority. Physicians call upon the authority of the mystery of the art of medicine in refusing to discuss with the patient what a scientific evaluation of his or her medical art might reveal. Similarly, some physicians use legal determinations of
what is required to be told to a patient to meet the requirement of informed consent in a given situation.

In arriving at his conclusion, Katz does not sanction what is at best the pseudo-scientific approach that views risks in terms of a cost-benefit analysis. For the patient consulting a surgeon about a malignancy in her breast, for instance, the risk of disfigurement may have more significance than the surgeon is able to understand. Such physicians usually adopt their own interpretation of risks without understanding the degree of their own self-interest involved in these definitions. For instance, for years, surgeons recommended radical mastectomies without any clinical evidence to support such uniform treatment of patients. With greater self-awareness, a surgeon might be able to inform a patient of the risks involved in radiation without surgery in such a fashion as to allow the patient to consult a radiologist without a loss of the patient's self-respect. It is far too easy for the physician, trained under the ethos of science, to attach to those who fail to follow his or her advice or orders the label of stupid, irrational, or even unscientific.

It is nearly impossible to teach about any issue of law and medicine without understanding how modern medical training and subsequent practice are grounded in modern notions of science. Although modern healthcare professionals do not conduct certified clinical trials, we are increasingly aware that the best of practicing physicians are in fact empirical scientists—not applied scientists—who improve upon their understanding of patients and the effectiveness of treatment through cases. Such practitioners are able to generate questions as they move from case to case and, in effect, learn to live with the uncertainties of their successes and failures. Katz's work on human experimentation provides a framework for explaining the successes and failures involved in applying scientific theories to human beings.

For lawyers, Katz's work on human experimentation helps them to resist two tendencies. First, it dispels the political-moral notion of some scientists that scientific research and human progress are inevitably linked. Some law-trained persons, as representatives of law, a conserving and slow-moving institution, are tempted to work to remove legal barriers to morally- and ethically-suspect medical practices under the guise of facilitating "progress"; by contrast, others see law as the last bastion against the technological domination of our lives and deaths. Katz's work suggests that a new moral order could emerge if law-trained persons learned to assess scientific issues in terms of the values law seeks to uphold. Such an analysis does not lead to an easy, narrow view of any particular medical issue that law must confront, but it does provide future practitioners of various professions with some of the skills necessary to resolve them.

Katz's analysis makes the neophyte physician aware of the importance of using science in shaping his or her perspective on patients, and his or her view on the appropriateness of interventions. The medical student at a prestigious medical school, for instance, quickly learns that status within the medical profession is linked to the biomedical research laboratory and the use of new techniques. Very little public or professional acclaim is afforded the surgeon who has consistently and competently performed routine procedures such as gall bladder removal. Rather, our public and professional attention is riveted on those surgeons who perform the more innovative and supposedly "heroic" surgeries—liver transplants, artificial heart implants, fetal cell transplants, etc. The young physician with Katz's perspective, however, is acutely aware that these are the procedures with the highest risks of mortality and that some presently accepted techniques such as mitral valve surgery started with 75 percent rate of mortality. To appreciate the value of "frontier" procedures, the young physician must first develop a perspective on the inherent worth of his or her craft or art by recognizing that caring for the individual patient is essential to the ethos of service of the medical profession.

For the undergraduates in Cornell's Biology and Society Program, many of whom are planning professional careers of some kind, Katz's analytic perspective encourages them to question whether the supposed scientific rationality, or the "technical rationality," as Donald Schon has suggested, provides the only basis for professional knowledge in practice. While concerned with the effects of modern biological developments in human medicine, environmental practices, and agriculture, these students are beginning to explore the meaning of "expertise" or "professional knowledge." They recognize that medicine occupies a high place in our thinking about professional knowledge, since the physician's practical knowledge is supposedly based upon "scientific" knowledge. It is here, within the first stage of the modern university, that we can begin to discuss the processes of knowledge creation, acquisition, and use in the service or disservice of human needs—what I will call "knowledge processes."

Let me illustrate knowledge processes by starting, in Katz-like fashion, with two questions:

Are the institutions of law and the family legitimate sources of authority for resolving the ethical dilemmas that modern medicine faces?

Or are physicians instead to look only to the institution of medicine in resolving the ethical dilemmas they encounter in practice?

We, as educated laypeople, know intuitively, for instance, that the question of continuing treatment for a cancer patient is not simply a technical matter for the
physician. Nor is it just a question for the family members, if there are any; for under some circumstances, particularly when children are patients, law might be asked to intervene. Yet I believe we are all tempted in this scientifically-oriented society to convert these questions in subtle and indirect ways into technical decisions. Few will actually argue that the physician alone should decide all ethical dilemmas, but unless we have a conception of knowledge or a means of presenting information across disciplines, we will be tempted to argue that only scientists should decide, or only physicians should decide, or only patients or judges should decide.

In reality we know that the social workers, hospital administrators, state regulatory officials, as well as family members are all part of the social community with some stake in the decision to continue or discontinue treatment. As I stated, tongue-in-cheek, in my long commentary on Katz's Experimentation with Human Beings:

Katz's major mistake, in my opinion, is that he wrote a law school text that intelligent laymen can read, understand, and enjoy. What will we lawyers do if non-experts understand our inadequacies in an important area such as human experimentation?

Katz's work is important because he gives us an analytical framework for talking across the disciplines and a way of framing the issues so that the educated layperson can participate in resolving ethical dilemmas of physicians, scientists, and other professionals or experts.

I have expanded upon Katz's framework in a seminar in the Biology and Society Program for undergraduates entitled "Institutions and Social Responsibility." In this seminar, students developed an analysis of some of the dilemmas of modern biology from an institutional perspective. An interdisciplinary group—a biologist, a social psychologist, an anthropologist, a philosopher, a teacher of English composition, a graduate student in sociology, and I, a lawyer—agreed, finally, on the objective of the course. A team of students would develop a "case study" around three broad topics: genetic screening, the bovine growth hormone case, and the right to die.

Katz's "Jewish Chronic Disease Hospital Case" was selected as the model case study in the best interdisciplinary fashion. While these undergraduates were, of course, unable to come close to matching the brilliance or the analytical rigor of Katz's work in their final written projects, their ability to synthesize diverse materials and apply their newly-found knowledge to their various problems was quite extraordinary. By the end of the semester, they were able to reexamine the question asked initially in the course—Is there a difference between institutions and organizations?—in light of the materials assigned in a way that came close to the Katz ideal of talking across the disciplines. This ability is particularly desirable for those educated persons who seek to exercise the authority associated with being called a "professional."

While the Katz framework helped the students learn to synthesize materials, it allowed me to develop a way of teaching about the problems of professional ethics from the multidisciplinary perspective espoused by Katz. If we recognize, at the most fundamental level, that most issues in professional ethics have as their basis some type of professional knowledge, what then is the source of that knowledge? In my view our modern conceptions of knowledge are aligned with the modern research university. Over the last hundred years, we have developed the extraordinary idea that universities are places where knowledge is created. Within this institutional construct of knowledge, society has developed organizational structures that represent particular kinds of knowledge. In the case of medicine we can think of "medical education" as an organizational structure that includes an undergraduate degree, a medical college degree, an internship, a residency, specialty training, and continuing education. To put the matter in Donald Schön's terms, these processes of certification and training constitute the "professional knowledge" that society expects the modern physician to have.

But modern society has a major organizational structure in which the physician and other health-care professionals operate—the hospital. Presently, however, economic and bureaucratic pressures could lead to change in that organizational structure, as health maintenance organizations, profit-making hospitals, and cost containment begin to dominate the national debate about health care in this country.
is apparent that the image of the physician as the "protector of health" or "the fighter against death" creates the ethical dilemmas that concern us. In addition, such grandiose characterizations as "preservers of life" create in the minds of physicians the illusion of an imperial mission rather than an attitude that is more reflective of their roles in society.21

I asked a group of medical students recently to consider whether being a physician or professional is a public or private role. Their initial response was to think of their ethical dilemmas as involving their private sense of values. But with further questioning, it became apparent that they needed to have a deeper understanding of their public roles which could accommodate conflicting values about the meaning of life, death, and disease. Arguing that physicians deal with public or social constructs such as disease allowed for discussion of physicians' roles and their performance of those roles.

But even more significant than the humbling effect on professionals of a social construct such as disease or death is the knowledge that other institutions such as the family and law deal with similar social constructs. In teaching about professional ethics, the analysis must be done at such a level that other disciplinary perspectives have relevance. The difficulty that we have in teaching about professional ethics is that we have too often conceived of the problem as a dyad between the professional and the client.22 Katz's work on human experimentation introduced me to professional ethics as a generic issue for modern society, not simply for the biomedical researcher but for all those who purport to exercise authority in the name of knowledge.23 Those of us who are not physicians should be aware that Katz's implicit message in The Silent World of Doctor and Patient is that, unfortunately, all modern professionals, including lawyers, approach their clients with silence rather than conversations about risks and about the client's and the professional's perceptions and biases regarding those risks.24

By proposing a way in which knowledge, organizational processes, and professions are interrelated, I believe that all students regardless of their pre-professional orientation or lack thereof will understand the importance of reflection while acting. Or, to use Donald Schön's phrase again, a practitioner is always engaged in a "reflective conversation" with the situation that he or she confronts in practice.25 The uncertainties encountered in practice—those cases that do not fit the book—are resolved though a form of on-the-spot experimentation.

Knowledge Processes and the Crisis of Higher Education

The universities, at least those that are comprehensive universities in the sense that they have undergraduate, professional, and Ph.D. programs, are in a peculiar position vis-a-vis knowledge processes. On the one hand, universities are supposed to "create new knowledge," be it in biotechnology or literary theory; such social posturing justifies the public and private funds devoted to research and graduate training. On the other hand, universities are supposed to provide the nation's "finest" youth, by some definition of meritocracy, with a superior undergraduate education. Among university administrators and concerned faculty members, it has been generally assumed since World War II that the undergraduate education function suffers because of the pre-dominance of the research function. This perceived dichotomy of research and undergraduate education ignores the possibility that a form of learning for undergraduates exists in comprehensive universities that is distinct from the type of learning taking place within traditional liberal arts colleges.

The undergraduate learning experience in the university could be consistent with the knowledge-creation function of the university, if we were to desist from thinking of all undergraduates as underdeveloped graduate students in pursuit of professional certification as knowledge seekers. We could then be free to think of the university as a learning environment where a coherent education for the undergraduate would be possible. In my view, such an undergraduate educational experience would have three components:

1. Opportunities for excellent formal learning experiences through superior instruction in classes, seminars, sections, and laboratories.

2. Opportunities for undergraduates to explore the frontiers of knowledge through participation in research activity.

3. Opportunities for mentoring from faculty members. We need to move from a procedural view of faculty advising to one in which the faculty member sees him or herself as the student's "coach" in the quest for knowledge.

If we accept the premise that an undergraduate education so constructed would be desirable, then the need for drastic reform of our present system is obvious. We might be tempted to go back to what apparently worked for some students in the 1950s, as Professor Allan Bloom suggests.26 Or we could argue that reform is not simply a matter of what Professor A or B does or fails to do in the classroom, but a matter of understanding the institutional processes of the university.

Such an understanding requires that we engage in some "institutional experiments"27 not only to discover the most effective course of action, but also to define the nature of the so-called crisis. A process of institutional
experimentation should recognize that there are purposes underlying "classical liberal education" that are worthy of respect. Additionally, we must understand that the rhetorical call for relevance of the sixties and the present concern for "skills" reflects a need on the part of undergraduates to assimilate the knowledge they perceive as relevant to their own anticipated work lives and their own sense of meaning. In other words, trying to change how teachers teach and what and how students learn should be seen as a process of human experimentation where deeply held values on the part of professors, students, alumni, members of boards of trustees, parents, and government officials come into play. In addition, this process of human experimentation requires the ability to articulate and debate a number of theories of knowledge, both old and new. For instance, the debate about whether "The Great Books" should include work by women, black, Hispanic, and Asian writers is in fact a debate about whether the structure of coherent knowledge is a closed or open system. Finally, this process of human experimentation requires an ability to reflect upon the methods of pedagogy in light of our emerging understanding of—and our students' perceived need for—the requisite, coherent knowledge of the twenty-first century.

It is worth noting that little systematic attention has been paid to those many undergraduates who enter the university with clear—for seventeen- or eighteen-year-olds—professional objectives. This is not to suggest that a narrow vocational curriculum for students within a liberal arts program would be the optimal education for these students, but it does ask us to consider what and how to teach. Should there, for instance, be opportunities for undergraduates to learn about law or medicine, not as professional disciplines, but as basic institutions of society? Should there be learning opportunities for teachers and students to engage in what might appear to be a professional activity such as a computer-aided design course for non-architects? Should experience in the performing or visual arts be part of a new concept of liberal learning? Might some learning activities be structured outside of the traditional semester mode of learning? But perhaps more important than the specific institutional experiments is:

By whom and through what methods should any such experiments be evaluated?

No specific proposals above should necessarily be adopted by any institution of higher education. These are merely examples of the type of reflection, analysis, and action or inaction that I derive from my understanding of Katz's thinking. His interdisciplinary approach to experimentation with human beings has influenced not only my way of teaching but my way of encouraging colleagues to develop institutional strategies for changing teaching and learning within the university.

In my view, any attempt to restructure undergraduate education illuminates a wider confusion about the purposes of research within the society. Those of us who are associated with universities too easily assume that the benefits of research are obvious to the larger society or at least to the policy-makers in the society. But recent criticisms of higher education and even some research indicate that the mission of the university as a social institution is not widely understood. To meet this challenge, we must rid ourselves of the simplistic view of the university as a collection of students and scholars seeking knowledge or the truth. Rather, we should see the university's mission as encompassing the broad functions of teaching, research, and public service. We should understand that professors, those with the highest form of authority within the institution, should conceive of their roles as forms of public service. The university professor is thus a professional, in the best meaning of the word, one who uses his or her expertise in the service of students and others in the society.

The Teaching-Learning Continuum: A Case in Point

In the course of the seminar I mentioned earlier, on Institutions and Social Responsibility, my graduate teaching assistant and I were faced with helping a group of students accommodate their differing perspectives on the development of the bovine growth hormone, a biotechnology that will radically increase milk production in dairy cattle. Since Cornell is one of the universities in which the potential of this hormone is being tested, the students had quickly understood the university's institutional involvement in producing and marketing this product. They also understood that this new product might ruin many small dairy farmers in New York State. But they had no way of organizing their often conflicting ideas; the research team was, in effect, stuck conceptually.

Fortunately, I had introduced my graduate research assistant to Katz's Experimentation with Human Beings as a way of teaching him how case studies are developed. Seizing upon the students' stalemate as an opportunity to put Katz's thinking about human research to practical use, he suggested they ask:

Who within the University is responsible for formulating the policy on the research involving the effectiveness of bovine growth hormone?

He further suggested they interview some of the key players on campus—a biologist doing the tests, a social scientist who had raised questions about the appropriateness of this research at a land grant university, and
an economist who had written widely about the potential social and economic effects of the bovine growth hormone. He went on to use the ideas of formulation, implementation, and review of the research process as a way of helping the students get beyond their idiosyncratic views of the problem.

That undergraduate students in 1988 find value in Jay Katz's work of nearly fifteen years ago is a fitting tribute to the power of that work. That a graduate student—a future professor—was able to use his work to teach others is an even more significant tribute to Katz as a scholar who always teaches. As his former student, I am enormously indebted to him for providing me with the tools to awaken within students that curiosity about the way the human mind works, which is, after all, what teaching is all about. As we ponder the direction of higher education, those of us privileged to have been associated with Jay Katz in our professional careers will continue to look to his wisdom for guidance. His work celebrates the best of university life, the creation, nurturing, and transfer of knowledge from many disciplines for the human good.

References


4. Whether there is a crisis in higher education might be debated, but it is apparent that the media and the general public are tremendously attracted to the pronouncements of the critics of higher education such as Secretary Bennett and Allan Bloom. Most recently, Bennett attacked Stanford University for changing its Western culture course to include works by "women, minorities and persons of color." Bennett, quoted in James Atlas, 'The Battle of the Books' New York Times, June 5, 1988, sec. 6; Schön illustrates a different aspect of the crisis as he points to a loss of confidence in the professions since the mid-1970's. See Schön, supra note 2, at 39.

5. See Gareth Morgan, Images of Organization (Beverly Hills, Ca.: Sage Publications, 1986), Ch. 2. This is only one view of organizations that we might have derived from science and technology. Morgan has also suggested that we might view the organization as a biological organism. See id.: Ch. 3.

6. Katz, supra note 1, at 96-95.

7. Palmer, supra note 1, at 237. In my commentary on Katz's book, I noted that: "Doctors, biological researchers, and technocrats, however, are not the only modern day high priests challenged in the book. To this order of high priests belongs any definable group that is given authority, because of its expert knowledge, to investigate other human beings or act in their behalf."

8. Katz, supra note 1, at 529; See also Palmer, supra note 1, at 248.


10. Katz, supra note 9, at Ch. 7.


15. Palmer, supra note 1, at 254.

16. The person from our writing program was present because this course was part of our attempts to increase the amount of writing in the upper class undergraduate curriculum and thus is part of a larger institutional experiment that we are conducting at Cornell.


19. Morgan, supra note 5.


22. See Palmer, supra note 11.


24. Katz, supra note 3.

25. Schön, supra note 2, at 141.


