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Volume 17, Number 1 (March 2001)

Hope and Responsibility in Clinical Settings: Two Reflections on Jewish Life and Death

Ethical Issues in Vulnerable Persons Research

Deborah Konia-Griffin, PhD Adeline Nyamathi, PhD UCLA School of Nursing

"Too Risky for Research? Human Research with Vulnerable Persons"

Wednesday, October 10, 2001 Presenters

Dr. Deborah Koniak-Griffin &

Dr. Adeline Nyamathi

The UCLA School of Nursing Center for Vulnerable Populations Research was established at UCLA in 1999. It has been funded by the National Institute of Nursing Research over the last five years as an interdisciplinary center. Immunologists are involved, as well as a biological researcher, behavioral researcher, and a number of professionals in public health. As our boundaries extend, we are offering a number of programs in different settings, community settings and other universities. At UCLA, we hold a monthly colloquium, including training workshops and consultation to faculty and students. For nursing there is an

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Are Scientific Truths the Only Truths?

James Walters Loma Linda University

A few years ago, I wrote up a case in which a 17-year-old Orthodox Jewish girl was diagnosed with a vaginal carcinoma. The only hope of curing her disease was to remove her vagina and uterus and then to treat her with both chemotherapy and radiation therapy. The treatment would leave her infertile. When the doctors informed her father of this, he was emotionally devastated by the diagnosis and the proposed treatment. He thought his daughter would be as well. Therefore, he asked the doctors not to inform his daughter that she would be sterile as a result of her treatment. He begged the doctors to withhold this difficult truth, and perform the operation with a consent from her that was clearly not informed consent.

His rationale was straightforward. He argued that she would tolerate the treatment much better if she had hope of a good outcome. Once she was treated and had recovered, he said, then the bitter news about infertility could be presented to her as a consequence of treatment. Furthermore, he argued, according to Jewish law, patients do not have autonomy as it is generally understood by secular bioethics. Lifesaving treat-

Physician Assisted Suicide continued...

ongoing pre- and post-doctoral trainingship in vulnerable populations. A variety of field experiences are offered for the pre- and post-doctoral students. We also have an annual research conference, which will be held in April 2002 in Palm Springs. One of our more recent activities is becoming involved with HIV Vaccine preparedness.

Four aims of the center

The major aim of the center is to advance knowledge about health related problems of vulnerable populations, by supporting ongoing research and new pilot feasibility studies designed to improve health status outreach for vulnerable populations. Each year we fund a minimum of three studies. These are pilot feasibility studies aimed at helping UCLA faculty develop research programs. Our budget from the government includes money that is designated just for this purpose.

Another aim of the center is to strengthen the resources for and the utilization of molecular, cellular, and physiologic assays in studies of the risk and health status of vulnerable populations. We have correlated in a bio-laboratory core that provides consultation to people who may be doing some behavioral research and are interested in biomarkers to be used in their research with vulnerable populations. We do the opposite in helping researchers learn some of the behavioral approaches as well. We also have the capacity to do some assays in our laboratory as well and give priority to our

pilot studies in terms of usage of resources.

A third aim is to enhance research support, particularly the development of supportive community networks in all phases of research with vulnerable populations. For example, we may help connect a researcher with a community that might become involved in any phase of the research. We are very committed to involving the communities from the very beginning phases. They actually help plan and design the research so that they are partners. We don't just go into a community, complete a study, leave and give nothing back.

A final role is to create mechanisms for interdisciplinary collaborations of scientists in both biological and behavioral research. We bring together people who tend to use qualitative methods with those who use quantitative methods.

Two special projects

We have two special projects. One is a Latino health demonstration project, the other a collaborative effort with the Los Angeles County health department. The Latino health demonstration project involves participatory research. The method implemented for this project involves the community from the very beginning, including asking research questions, seeing what questions are appropriate for the studies, and disseminating back to the community with results of the studies. We've used this technique with Venice Family Clinic in designing a study, which now is a collaborative study and is under review for funding. It relates to culturally competent diabetes education. We attempt to show

that nurses from the same Latino background who use certain culturally appropriate strategies have very effective outcomes with these poor and often homeless Latino diabetic patients.

We have a second project that is collaborative with the community of Los Angeles County through the county health department. The project involves training lay health advisors, who are community outreach workers, to do general health promotion through their churches and through the schools. So this is a project where they use their own social networks to help improve the health of the people they know.

HIV vaccine preparedness

As we all know the HIV/AIDS epidemic continues. The anti-retral-viral Please turn to page 3

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Physician Assisted Suicide continued...

drugs and the protease inhibitors are not going to curb HIV worldwide and normal HIV transmission will not be stopped by behavioral interventions alone. So, as a result, there is an increasing interest in HIV vaccine. We want to know how to get involved with HIV vaccine preparedness. Some of the core leaders of our center have been involved in doing HIV risk reduction studies for some time. In fact we have had very favorable outcomes from our studies. Our interventions have resulted in some improved behaviors and less risky behaviors. So overall the results of these studies on an individual basis has been recognized to be positive, but we know that we need to do more. Behavioral interventions alone are not going to solve the HIV epidemic from particularly a global perspective. We became interested in vaccines as another developing approach that needs to be done simultaneously. We began to explore what was happening in vaccine research, what we realized very quickly was that as the

researchers were moving ahead with HIV vaccine preparation in terms of biologic end, the person end, the behavioral end, was not being addressed as much. When we use the term "HIV preparedness", we intend to focus attention upon the issues, ethical and social, that participants in these trials might have. We became involved in a workshop, recognizing that 53 million people were infected with HIV worldwide, 19 million have already died, more than 13 million chil-

dren have been orphaned, and there are 16,000 new cases every day. Ninety-five percent of these cases are occurring in developing countries, so it is a global problem that we all have to address and be concerned about. We decided to do a vaccine preparedness think tank held August 29, 2001. We pulled together an interdisciplinary group, which included researchers from UCLA, community representatives, people from the county health department, and some pre and post-doctoral fellows. It was purposefully designed to be interdisciplinary and to involve the community so that this would be a beginning phase for strategic planning in terms of HIV preparedness.

As you are all probably very well aware vaccine trials have been going on for some time. However it is often said that ethics and social policy lag behind advances in medical technology. We are trying to address this ethical area related to HIV vaccine preparedness so as not to lag behind. There is a lot of concern about HIV preparedness and being in HIV vaccine trials for many reasons. We must never forget what happened at Tuskegee and that is a big factor that we need to keep in mind.

Awareness of this tragic study is widespread in the community and particularly among vulnerable populations and directly impacts how people respond to us. I know that going out to the areas where I do my research in East Los Angeles, and saying that I am from UCLA is not necessarily a big plus at all, there is a big trust and mistrust issue and so the trust has to be developed. Tuskegee is one of the most dramatic examples that I can give you that you need to keep in mind when you work with people.

Three types of trials

We can "remove the

impediment" to

natural death, but can

take no direct action

to kill, as we see in the

story of Rabbi

Chanina.

We have three types of trials; phase one, phase two, and phase three. Currently, we have over 10,000 people who

have been through the various trials. We know of one large ongoing trial that is a phase three involving over 5,000 people. UCLA has a number of trials that they are recruiting participants for right now. Phase one trials focus low risk participants and a smaller sample to test the safety of vaccines. Whereas phase two trials are conducted with medium to low risk participants and they have a little larger group of participants. Phase three are efficacy trials

with moderate to high risk patients involving several thousand people. In order to get FDA approval of the vaccine we really have to have these vaccines go through these three phases and show that they are safe.

Two types of vaccines

There are two types of vaccines being tested; preventive vaccines and therapeutic vaccines. Preventive vaccines are those given to people who are not infected and they either try to block the HIV from being transmitted or prevent the organism from developing into the disease. Where as therapeutic vaccines are for HIV infected individuals and they try to boost the immune system so that people can comeback from the disease and do better.

Physician Assisted Suicide continued...

Vulnerable populations and how we define them

We see vulnerable populations as social groups that have an increased susceptibility or higher than the national risk for health related problems. While we recognize there are numerous groups that represent vulnerable populations, we are focusing on ethnic people of color and low-income people. We also recognize women and children as vulnerable for populations. Very little research has been done on women and children, because they don't necessarily benefit in the same way that other groups do. Homeless people are vulnerable as well as people exposed to hazardous conditions and polluted environments such as, some of the migrant farm workers.

Social concerns of trial participants

As clinical trials are underway we feel a pressing need to take a closer look at the ethical and social concerns of trial participants and their communities. We know that many people would be very interested in vaccines if the social and political climate was fine and the vaccine we possessed was highly effective. Hopefully, under those conditions, we wouldn't have to do very much community preparedness. However, because this is unlikely in the near future, empirical, focused, cooperative attention by both scientists and the community at risk is needed.

We know from several qualitative studies that have been done that there are a number of benefits from participating in a trial. There is a CDC funded study called Project LINKS that connects scientists and communities together. This project surveyed African-Americans from Durham, South Carolina, injection drug users from Philadelphia, and gay men and women from San Francisco. Very positive attributes of the trial were spoken of by the participants, such as being invited to participate. Injection drug users especially felt they face risks everyday in their lives taking street drugs. Now why wouldn't they become involved in the project? We feel it makes sense for them to engage in such research.

However, we must comment on the parallel concerns and issues raised. There are a number of risks and concerns regarding the vaccines themselves. These include negative side effects, the unknown safety of these vaccines, development of HIV antibodies, the risk of contracting HIV/AIDS if an attenuated virus were to be given, restrictions of travel, inability to join the Peace Corps, inability to donate blood or organs, inability to receive future vaccines determined to be most efficacious, and discrimination. For example, injection drug users also said that their street buddies were more comfortable with the street drugs and had more faith in the street

drugs than they did in the government. And we hear from still more injection drug users and gay men and women how they feel the government has done nothing for more than ten years and that they believe their population was actually targeted. They feel the government places little or no value on them as a population group. We would concur that minority communities have been victimized by the government, visa-vi research abuse, government neglect and social discrimination. Many African-Americans actually believe that the HIV/AIDS epidemic is a biological experiment that has gone wrong. That is the type of perspective that we hear all the time. People from minority communities tend to ask us, "Is there a reason they are targeting high risk individuals? Is it perhaps because we're less sophisticated? Is it because we don't ask the difficult questions?"

The social consequences of participation include the impact of these vaccines with family, friends, life partners, insurance, and employment. We have heard from individuals asked to participate in a vaccine trial that they would increase their risk behavior because they feel a sense of protection from the vaccine, even though they have no sense of what the efficacy of the vaccine might be. Often times when somebody receives the vaccine they will then test sero-posi-

Scientific Truths as Only Truths continued...

ment is obligatory. Therefore, his daughter could not refuse treatment. Thus consent was not really a central issue.

Needless to say, the doctors were uncomfortable with this approach. An ethics consultation was requested. The main question was, "Do we have to tell her that she will be infertile?"

In one sense, this was an easy case. From a riskmanagement point of view, it was a "no-brainer." You tell her and if she refuses treatment, that's her choice. It may be tragic but it isn't a tort. If you treat her without consent and she sues you later, it is at least malpractice and may be assault and battery. From a bioethics perspective, these legal considerations reflected appropriate moral concerns. Fundamental understandings of informed consent, respect for persons, and the obligation to tell the truth all suggested that the patient should be told that she would be infertile. Not to tell would be paternalistic, and, in bioethics, there is no greater sin than paternalism, although that might be hard to explain to her father.

But from another perspective, it seemed a little more complex. Were we really concerned about the patient's interest or about the hospital's? Whenever ethics and risk management agree, a red flag should go up. Furthermore, legal and moral principles we were relying on were neither timeless nor universal. If she had not been in the United States, or it had been

twenty-five years earlier, nobody would have told her. She was a minor. Her parents had the right to make decisions for her. In addition, her religion did not acknowledge the importance of autonomy. As her father said, "She must have the treatment. It is required by law. Why add to her suffering now, when she needs hope and strength." Clearly, he had her best interests at heart.

Ethics committee review of the case led to some bitter disagreements about the limits of disclosure, the obligation to tell the whole truth, the constraints of autonomy in the context of a religious tradition that did not emphasize or even believe in autonomy, gender issues, paternalism, multiculturalism and many other issues. The case clearly touched a lot of raw nerves. No consensus was reached. However, most people thought that the girl ought to be told, and that is what the attending physician decided to do.

At a family conference, he told the girl and her parents that treatment was her only hope for survival and that it would definitely leave her infertile. He told her that without the treat-

ment she would certainly die. The discussion was heart-rending. The girl and her parents were clearly grasping for straws of hope. They asked about whether she could donate eggs, about uterus transplants, about gene transfer techniques, about cloning. The doctor was steadfast in sticking to the facts as he saw

them and in refusing to offer false hope. He told her that she could not donate eggs, that there was no chance now or in the future that she could have a uterus transplant, and that without a uterus there was no way to become pregnant or to have a child. These were all true statements. Brutally, unimaginatively true.

After hearing all this information, the girl ran crying from the room and refused to consent to the surgery or to any other treatment for her cancer. A few days later, however, she returned. She signed the consent form without reading it. It was a baffling reversal.

Further investigation by the social worker revealed that, in the interim, she had talked to her rabbi. He had assured her that there were limits to what the doctors could know or do. If God wanted her to become pregnant, her rabbi told her, she would become pregnant. Perhaps this reassurance helped. Perhaps she reconsidered her decision for other reasons. Perhaps there was pressure from her family. We don't know exactly what happened. But she changed her mind, signed the form, and underwent surgery, radiation treatment and

chemotherapy. She responded well to treatment and returned home. We later learned that she had married and she and her husband had adopted two children.

The case raises a number of interesting issues, but the one I would like to focus on is the difference between the rabbinical and the medical approach to truth-telling and informed consent. Specifically, I would like to think about whether it would have been dishonest or misleading for the doctor to have said what the rabbi said, namely, that even after a hysterectomy, it would be possible to have children if God wanted her to have children. Put another way, are scientific facts the only valid facts for scientists and may nonscientists choose a different set of facts? Or are the truths of science universal truths, so unwillingness to believe them constitutes self-delusion, and propagating them constitutes virtue? It seems as if what the doctor told the girl and what the Rabbi said cannot both be true, that is, it can't be true. But which truth should the doctors affirm?

Doctor as Materialistisic Scientist

There are a couple of ways to think about the doctor's role and responsibility in such a case. One is to imagine a doctor

Whenever ethics and

risk management agree,

a red flag should go up.

who does not believe in God and is not at all religious. We might think of such a doctor as a thoroughgoing materialist and scientist. She would believe that the only truths in the world are those that have been tested by experiment or clinical trial. Such a doctor would think of religion and religious beliefs as mere fairy

tales, or worse, as dangerous hypocrisy left over from an unenlightened age. For such a doctor, the question of whether a woman without a uterus could ever bear children is an empirical question. The answer is straightforward. It is clearly impossible. Thus, it would be immoral and unethical to suggest that it might be possible, and it would be irrational to invoke a mystical, transcendental concept such as God as a mechanism for the impossible.

Such a doctor has a faith in the truths of science and the limitations of the material world that is as deep and abiding as the faith of any mystic in the truths of religion or existence of a transcendent spiritual world. For such a physician, I would argue, a statement about what God might do would not just be a lie but would be a fundamental betrayal her own deepest held beliefs. She would be dishonest to both the patient and, perhaps more importantly, to herself. She would have a moral obligation to behave as the doctor in our hospital behaved.

However, and this is crucial, that obligation would not have derived from a general moral theory of truth telling so much as

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it would have derived from a more personal set of beliefs about what constitutes the truth. The doctor would have a moral obligation to herself tell the truth as she saw it or believed it.

Doctor as Compassionate Consequentialist

Another situation would be where the doctor was not such a deep believer in science but was not particularly religious either. For such a doctor, the mysteries of science and the mysteries of religion would seem to be equally arcane and unapproachable, perhaps even beyond understanding. Such doctors might recognize and even admire true scientists and true religious believers, but would not consider themselves to be either. (This group might comprise the majority of doctors today.)

For this doctor, either a statement that the woman could never have a baby or that God might allow her to become pregnant after a hysterectomy would both be tentative, and thus both would be possible. Such a doctor just wouldn't know for sure.

Such a doctor, presumably, would be less committed to any particular idea of truth than to an ideal of compassion. Compassion is certainly a central element of what we expect from our doctors. It is sometimes difficult to determine exactly what compassion demands. By an appeal to compassion, we could argue that it would be okay to say anything that would make our patients feel better, even lies. Some might argue, however, that in the end, telling the truth is the most compassionate response, and that a lie up front will not only make the truth hurt more later, but will destroy the future possibility of a trusting relationship, and thus destroy the possibility of compassion down the road.

This is a traditional dilemma for doctors. For centuries, doctors have claimed the right to withhold difficult truths in order to make patients feel better, to engender hope, not destroy their will to live. The sentiment behind such arguments is that doctors have as their single goal the best possible outcome for the patient and in pursuit of that goal, moral transgressions such as little lies are not only acceptable but obligatory.

Alternatively, such a doctor might argue that, in the long run, patients do best when they are told the truth. Telling patients lies destroys the trust that is the essence of the doctor-patient relationship. The patient will no longer believe anything the doctor says, and so, her future care will suffer. Honesty about outcomes is important because a trusting relationship between doctor and patient is important. Thus, the argument might go, even from a consequentialist position, we are better off telling the truth.

The consequentialist argument can lead in either direction but, interestingly, it does not rely on a belief in any particular form or structure of truth. In essence, the truth is what works. The doctors' allegiance ought to be to whatever will lead to the best outcome. Sometimes that may be science and its truths, sometimes it may be religion and its truths, and sometimes they are in harmony and a choice might not have to be made. Such a doctor might learn from the rabbi in this case, and adopt a faith-based approach as just one of the tools in his conversational armamentarium. Thus, whenever he feels a patient needs hope, he might say, "Well, all the studies show that your cancer is untreatable, but if God wants it to be cured, it'll be cured."

Such a doctor raises the question of whether doctors should be guided by allegiance to any form of truth or belief or whether, instead, they should be guided by some other sort of moral obligation and see truth as necessarily malleable, but the duty of compassion as absolute.

Doctor as Religious Believer

What about the doctor who believes deeply in God and in miracles? Could such a doctor speak as the rabbi spoke? Would it have been acceptable for such a doctor to say, as the rabbi said, that if God wants a girl without a uterus to have children, she will have children?

It seems that such a doctor might be in a position that is analogous, in many ways, to that of the first doctor, the scientist. That is, he not only could say this, but he must say it. Not to believe this would betray his own most deeply held personal beliefs.

But a different sort of problem arises for such a believer. At some level, absolute faith in God to perform miracles that go beyond science becomes incompatible with medical care. If one's faith was so deep that one thought of all disease and healing as under God's control, then the whole enterprise of scientific research, medical care, and therapeutics, would seem a bit absurd. What, after all, are we trying to prove by developing treatments to interfere with or modify God's will? It seems that even the most deeply religious physician must believe to a certain extent in the laws and truths of science, and must be able or willing to say that something is scientifically impossible. Perhaps only a rabbi, that is, only a nonphysician, could stand outside the world view of medicine and science to a sufficient degree see all the ravages of disease and works of the physicians as occurring on a different level than God's work.

This view necessitates a philosophic split between the technical work and truths of medicine on one hand, and the spiritual work and truths of a different sort on the other. Medicine becomes a mundane and decidedly value-free, despiritualized activity. It also raises the question of whether the morality of the physician comes from a sort of professional morality, a set of role-specific duties and obligations or, by contrast, whether the physician ought to be so value-neutral

that whatever values he incorporates into his practice must be imported from the outside?

Religion, Truth-telling, and Internal Morality

The conflict between an internal ethic of the profession and an external ethic for the profession energizes one of the more interesting debates in the field of bioethics. Stated simply, the question is whether medicine is primarily and intrinsically a moral enterprise, with its own internal values and norms, or whether it is primarily a technical and scientific enterprise which is morally neutral until society, culture, or individual patients bring values that imbue it with moral purpose.

Leon Kass, in a series of remarkable and deeply insightful essays, argues strongly that medicine is essentially a moral enterprise. He elucidates the continuing relevance of the Hippocratic oath and other ancient Greek ideas about the nature of health and disease and about the virtues and the ends of the medical profession. Those ideas, he believes, still define

the core morality of the profession. Today's problems, in Kass' view, derive from an inattention to these values, and today's solutions can come only from a return to them.

Edmund Pellegrino also argues for a return to and a reasserting of Hippocratic ideals. Medical ethics, he writes, "is not a matter of social convenience, alterable by political social or economic exigency or by public referendum. Any ethic changeable

by fortuitous social, economic, political or legal fiat ultimately ceases to be a viable ethic." 2 Like Kass, he calls for a return to and rearticulation of ancient moral values as the only hope for saving the medical profession from what amounts to a hostile moral takeover.

By contrast, many bioethicists feel that medicine is a technical, rather than a moral enterprise. In this view, doctors' expertise is as morally neutral as that of electricians' or auto mechanics' and the Hippocratic oath is a narrow, sectarian, and elitist code that represents only the particular values of a particular group of physicians. Some doctors or patients might choose these values but there is nothing universal about them.

For a doctor to claim any moral authority is, according to Robert Veatch, a serious fallacy which he calls the "generalization of expertise." Doctors' expertise, he argues, is strictly technical, not moral, and the ends to which it is put are strictly moral, not technical. Therefore, doctors ought not to speak about ends. In an article Veatch wrote with Spicer, for example,

they condemn professionals who "persist in believing that they can determine, based on objective knowledge and their medical skill, what will benefit a patient and what will not." Such judgments, they think, require the incorporation of values, and "clinicians cannot claim expertise in value judgments." 3

Similarly, Troyen Brennen discusses what he calls "just doctoring" and calls for a balance between a traditional medical morality, in which the physician would do everything possible that might benefit his or her individual patient, and the demands of modern liberalism, which require the physician to consider and incorporate society's economic and institutional concerns.4 Brennen remains sympathetic to the physician but like many other philosophers, economists, and policy makers, sees that the doctor's traditional moral commitment to do everything for each patient presents society with an infinitely large and ultimately unpayable bill for services. Such economic tensions, like the moral tensions articulated by Veatch and Spicer, lead inexorably toward external controls on the content

of medical practice.

There seems to be a wide gap between those like Kass and Pellegrino who believe that medicine should be rooted in the internal values of the profession, and those like Veatch and Brennen who see medicine as necessarily embedded in and accountable to a particular political society. Nevertheless, there is a common thread in all of their arguments. All see the current situation in health care as an unsat-

isfactory compromise of moral norms. For Kass and Pellegrino, it is a compromise of the Hippocratic norms which they see as central. For Veatch and Brennen, it is a compromise of the political values that govern all aspects of our society and which should clearly govern medicine. Each of these thinkers calls for an explicit articulation of a political and moral program which would be different from today's melioristic status quo.

We seem to want it both ways. We want to think that there is something inherently and intrinsically moral about the profession, that there are certain things doctors should or must do because they are doctors. We like the idea of a profession with its own internal moral code that dictates responses to moral dilemmas. This view offers us some reassurance about what doctors will or will not do. But lately, it seems, we don't want doctors paternalistically imposing their values on others. We want to think that the patients' values should drive decisions and that doctors need to curtail their own morality. Informed

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Specifically, it becomes faith in our doctor's ability to distinguish facts from values, reality from hypothesis, knowledge from bias.

consent, shared decision making, the growth of modern biomedical ethics, health law, and manifold regulatory controls on doctors all bespeak a rampant distrust of doctors as individuals and as a profession. By this view, we want doctors to be value-free technicians, offering their services to individuals, insurance pools, and the country as a whole, but in ways that are guided and determined by the policies of ethics committees, legally determined standards of care, or democratically determined allocation plans or practice guidelines. We want it both ways.

In a curious way, the rise of bioethics necessarily contributes to the gradual but inexorable demoralization of the medical profession. Nonpaternalistic doctors who do not have or impose their own values on clinical situations are, in essence, amoral technicians. They should defer to somebody else–patients, philosophers, clergy, or democratic populace speaking through referenda–to supply the values.

The irony of this view is that medicine that is narrowly self-contained in this way and does not rely on any particular philosophy or value system becomes, in itself, a type of faith. Specifically, it becomes faith in our doctor's ability to distinguish facts from values, reality from hypothesis, knowledge from bias. We need to imagine that there is and can be such a thing as a value-free doctor at the center. Anyone who believes in this mythical construction, in spite of a century of anthropologic, sociologic, and cultural criticism that shows how inevitably embedded we all are in the world views of our particular culture, must be as passionate in his beliefs as any mystic.

To return, then, to the case I started with, we might ask whether the doctor was really giving the patient "the facts" or whether, instead, each fact was a decision, a judgment, a prophecy. Why not imagine that someday a uterus transplant might be possible, or human reproduction by cloning? Why not imagine that we will discover ways to bring about the regeneration of organs? How do we know what is or is not possible, or will or will not be possible? The true scientist could never talk dogmatically and self-assuredly to a patient about what the

future will bring.

We live in an age of uncertainty. In medicine, we know more about disease and treatment, and about the relief of suffering, than doctors have ever known. We can erase pain with an intravenous solution, ease the ache of depression or anxiety. We manipulate consciousness, emotion, and memory. We also know, or should know, how little we know, how inadequate we are to the scientific and moral challenges we face. How should we live? What does it mean to care for one another? How best to share another's grief, to help carry another's burdens? These are the big questions, and we are no closer to answers than we were a thousand years ago, when there were plenty of doctors but no penicillin, open heart surgery, or bioethics.

Perhaps the only way we can learn what to say and do is by putting ourselves into situations where we and our beliefs are tested. I sat in the room with that 17-year-old who was watching her hopes and dreams vanish before an onslaught of information delivered dispassionately and idealistically by a zealous modern doctor. And I heard a rabbi meet her in her fears and speak to her longings. I realized that I wanted to live more like the rabbi. It seems apparent that, in order to do so, honestly, I may need to learn how to believe more deeply in a God powerful enough to give such a woman children. It would not be enough to speak the Rabbi's words. That would be offering only glib reassurances. Instead, I would need to learn a different way of thinking and responding in the world. I would need that in order to keep sitting in such rooms, to keep engaging my patients in the terrible conversations I must engage in, to maintain some sense of my own purpose. This is to say, I may need more faith in order to keep practicing medicine.

- 1 Kass L. *Toward a More Natural Science*. The Free Press. New York. 1985.
 - 2 Pellegrino, E. "Ethics." JAMA 1996;275:1807-9.
- 3 Veatch, RM and Spicer, CM. "Medically futile care. The role of the physician in setting limits.", *American Journal of Law and Medicine* 1992; 18:15-36.
 - 4 Brennen, T. Just Doctoring. Harvard. Cambridge. 1992.



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