

forms dilemmas for caregivers in understanding their professional duties—to patients, colleagues, and others. Questions include not only how the scope of the professional-patient relationship is defined, but also how factors outside that relationship, such as physicians' investment in diagnostic centers, influence it.

The second section—"Informed Consent"—explores questions about how decisions regarding medical treatment are best made, and who is best situated to make them. For example, do patients need to know how experienced their physician is before they can give truly informed consent? Can physicians withhold treatment they believe is futile without discussing that decision with patients? Case studies also examine how decisions are made for patients, such as children, who cannot decide for themselves.

Cases in the concluding section—"Privacy and Confidentiality"—consider especially the privileged character of the relationship between patient and caregiver and professionals' duty to safeguard confidential information. Among the questions raised in this section are how to balance the potential harm done to the patient by divulging privileged information against the possible harm of not telling others who may be profoundly affected by that information.

PROFESSIONAL CONDUCT

1

When the Doctor and the Minister Disagree

Mary Clarkson is fifty-five years old; for the past eight months her husband, Bill, has been in California settling the estate of a relative. He comes home once every two months for a weekend visit and then returns to California. Mrs. Clarkson has been feeling depressed and lethargic; she voluntarily admits herself to the psychiatric unit of a community hospital seventy-five miles from home.

Mrs. Clarkson is very religious and has been attending church with her sister and brother-in-law. Upon admission to the hospital Mrs. Clarkson calls her minister, Rev. Tark, and asks him to visit her.

During the visit Mrs. Clarkson tells him about her marital problems: She and her husband constantly argue about his absences and how to deal with their thirty-year-old son who has had recurrent emotional and financial problems. Mrs. Clarkson feels guilty about not giving her son more money and support, and she wants to help him solve his problems. Her husband, however, wants nothing more to do with him. Rev. Tark offers her absolution after her "confession," and prays with her for strength to get well and to return home.

The next day Rev. Tark receives a call from Mrs. Clarkson's psychiatrist, Dr. Vern. Dr. Vern wants to know if Rev. Tark has visited Mrs. Clarkson and what was said. Rev. Tark explains that he saw Mrs. Clarkson at her request and that he heard her confession and offered her absolution.

Dr. Vern states that Mrs. Clarkson would be better off if she saw only him for counseling during her three-week stay as an inpatient. He feels that her depression is the result of a failed marriage and that she can only recover when she acknowledges that fact and begins proceedings for separation. Rev. Tark disagrees that the marriage should be ended. His goal is to help resolve the difficulties, which he thinks began when Mr. Clarkson retired from his factory job, at the age of fifty-five, about a year and a half earlier.

A few days later Rev. Tark's superior receives a letter from Dr. Vern, in which he states that Rev. Tark "must get clearance from the attending psychiatrist for any contact he is to have with the patient during hospitalization." After Mrs. Clarkson is sent home she will be free to choose whom she wants to see for counseling, the letter continues, but in the hospital the presence of her minister will only undermine her medical treatment.

Should Rev. Tark return to see Mrs. Clarkson in spite of Dr. Vern's ban? Does Mrs. Clarkson have the right to choose her counselor? Do patients "belong" to any professionals?

COMMENTARY

Robert Weikart

The case suggests several ethical issues: informed consent, autonomy vs. paternalism, beneficence, and respect for differing belief systems. The patient is directly involved in the first and last issues, while the psychiatrist and clergyman are involved in the middle two.

In considering informed consent, it would be helpful to know what Mrs. Clarkson was told upon admission to the hospital. Was she told that her visitors would be limited? Was she told that the psychiatrist would determine whom she could see? The case does state that Mrs. Clarkson called Rev. Tark "upon admission to the hospital" and requested a visit. Either she was informed of a visitor rule and had disregarded it or was not informed and subsequently invited specific people to visit her. Since she was depressed and lethargic upon admission, it could be a positive sign if she has called upon those who can offer her support with or without the approval of her psychiatrist.

Assuming that Mrs. Clarkson is competent and was not told that her visitors would be restricted, she was treated paternalistically. Paternalism usually protects someone from hurting himself or herself or others or protects the individual who is incompetent to make decisions. Paternalism presupposes that the physician will act only in the patient's best interests. It also gives the patient the right to negotiate the bounds of such paternalism. But in this case the patient's best interests were not served when her minister was asked not to return, with no negotiation about the extent of paternalism.

Those who would favor paternalism in this case might argue that Mrs. Clarkson does not know what is good for her and needs the guidance of a professional. However, if we accept this argument, was she competent to admit herself initially to the hospital and to ask her minister to visit? If she is conditionally or intermittently competent, who makes that diagnosis?

The psychiatrist also faced a conflict of interest. Can a psychiatrist who works for a hospital psychiatric unit be beneficent toward patients while also being an agent of the institution? If the institution prohibits visitors for new patients but the psychiatrist deems visitors helpful for patients, which side will he uphold?

At the crux of this discussion are Mrs. Clarkson's religious beliefs. Since she has been attending church with her relatives, it appears that religion is important to her. She also seems to believe in the sacrament since she participated in confession and absolution with Rev. Tark.

Her faith raises several questions. How does Mrs. Clarkson view divorce? If she views it as a sin, and is encouraged by Dr. Vern to leave her husband, she may have feelings of guilt and a sense that she has lost grace with God.

There is some overlap between what clergy and psychiatrists do, and this seems to be part of the problem. In this instance, the minister is dealing with the sacramental aspect of her life, which affects how she lives her life. The

WHEN THE DOCTOR AND THE MINISTER DISAGREE 5
if psych. believes guilt is religious part of her
psychiatrist is concerned with her marital situation, but needs to consider pushing
her religious values as well. and clergyman

After the inpatient treatment is finished Mrs. Clarkson will need ongoing support. She will probably see Rev. Tark as she did before. There is some question, however, about whether she will continue to see Dr. Vern since he is affiliated with a hospital far from her home. Rev. Tark can provide continuity of care as well as support for her religious beliefs.

If Dr. Vern thinks it unwise for Mrs. Clarkson to see Rev. Tark, he should meet with Rev. Tark and explain his reasons. Dr. Vern also should enlist Rev. Tark's help in resolving any guilt generated by Mrs. Clarkson's decision, if she makes it, to divorce her husband.

I believe that Mrs. Clarkson has the right, especially if she was not previously informed otherwise, to see the professionals she chooses. Her beliefs are important to her and need to be sustained as a resource both for the present and the future. incl.

COMMENTARY

Howard Klar

Competence definition
who decides
how?

Psychiatric disorders, more than any other group of medical problems, are shaped and influenced by the social and cultural milieu in which they occur. When changes in a person's emotional life lead that person to seek treatment, the psychiatrist's obligation is to consider sociocultural factors, as well as many others that may be contributing to the patient's problem. After carefully assessing the problem from these different frames of reference, the physician can integrate biological, social, and psychodynamic factors in order to arrive at a plausible explanation. Then, with the patient's consent, effective treatment can begin.

Dr. Vern did not fulfill this responsibility to his patient and Rev. Tark could not, due to a different orientation, fulfill this responsibility either. As a result, a travesty of clinical care occurred.

Mrs. Clarkson is a woman with a shaky marriage, a troubled son, a guilt-ridden conscience, and perhaps, a biologic propensity toward depression. Given the turmoil in her personal life, it would not be surprising if Mrs. Clarkson were also troubled by thoughts and feelings that are at odds with her strong religious beliefs. Despite her regular attendance at church services, she is unable to find solace from her depression solely through religion. She then voluntarily seeks medical care in a hospital. Implicit in this decision is Mrs. Clarkson's belief that Rev. Tark's counseling alone could not help her overcome her depression.

When patients enter the hospital they have the right to expect that the medicine practiced there will be grounded in science and that the practitioners in the hospital will be credentialed professionals. They further have the right to assume, in most cases, that they will participate in all decisions re-

garding their care, including decisions about who can and cannot provide care in the hospital. Patients do not retain the right to choose anyone to treat them in a hospital, particularly if they seek a treatment not acceptable by the hospital's standards. *e.g. religious?*

We never know if Rev. Tark views himself as a practitioner, only that Dr. Vern finds him intrusive. Interestingly, both men seem to have a point of view regarding Mrs. Clarkson's marriage. One wants to save the marriage, the other seeks to end it. What does the patient want? Neither Rev. Tark nor Dr. Vern seems to care. Mrs. Clarkson is not mentally incompetent, therefore she does not need to be told what to do. She may require time to struggle toward a decision about her marriage, but it is her decision to make. The two men are engaged in a struggle to impose their points of view on Mrs. Clarkson, not in a discussion of how to help the patient.

Banning the minister from seeing Mrs. Clarkson is Dr. Vern's trump card in this test of wills. There is no question regarding a hospital's right to restrict visitors if the visit is harmful to the patient's condition. Whether Dr. Vern was correct in interpreting Rev. Tark's visit as harmful is another matter. Certainly, "confession and absolution" are not medical treatments for depression. However, religious beliefs obviously play an important role in understanding Mrs. Clarkson's problems, and the potentially positive role Rev. Tark could play in her treatment should not be underestimated.

Rev. Tark was fulfilling his professional role and attempting to help his congregant. We should not expect him to be aware of the complex issues involved in the treatment of depression, that is, to behave like a physician. We may even be inclined toward a more forgiving stance toward his trying to "save the marriage," without placing Mrs. Clarkson's wishes first.

Dr. Vern was wrong to deny the minister his right to visit Mrs. Clarkson. While the minister may have been misguided, he was clearly not dangerous or harmful to the patient. As a psychiatrist, Dr. Vern's professional obligation to his patient is to be aware of the multiple factors impinging on her clinical condition. To suddenly deny her access to her minister, without even consulting her, is clearly an abridgment of her rights.

Physicians in the hospital setting are granted enormous authority over the care and management of their patients. It is reasonable to expect that this authority will be used fairly and in the interests of the patient, not to prevent the patient from hearing points of view that differ from the physician's.

Hospitals rightly impose limitations on the freedom of patients to choose both treatments and "treaters." While this restriction protects patients from snake-oils and charlatans, it also requires that the physician in charge exercise judgment regarding the role of "nonscientific" factors, like religion, in a patient's treatment. If Rev. Tark and Dr. Vern cannot work out their differences, then Rev. Tark should call Mrs. Clarkson and explain the dilemma. Mrs. Clarkson would then be free to discuss it with Dr. Vern and seek another medical opinion, or even to leave the hospital.

Every profession carries with it a set of values and obligations. The conflict in this case occurred when the professional values of Rev. Tark collided with those of Dr. Vern. While both men lost sight of the patient's right to find her own way, even within the constraints of being in a hospital, Dr. Vern lost sight of the values of his profession—namely, to make use of the patient's values and psychosocial supports in her care, rather than to further alienate her from them.

*research
conscience
literature*

2

The Nurse's Appeal to Conscience

Alice Howard is a registered nurse at Hillside Nursing Home where she cares for Jane Barnes, a sixty-three-year-old woman who has terminal colon cancer. Mrs. Barnes is in considerable pain, which has been increasingly difficult to control. The attending physician, Dr. Jones, has ordered moderate doses of morphine. The family understands that at these doses morphine may depress respiratory effort, thus hastening death.

In the past months, Mrs. Barnes and her family have moved toward acceptance of death. Some member of her family is with her constantly to comfort her. She is receiving morphine as often as every three hours and her sleeping respiratory rate is now very slow.

Most of the nurses see no problem with giving morphine to Mrs. Barnes. However, Nurse Howard disagrees. She believes that the morphine will cause Mrs. Barnes to die earlier than she would have otherwise; thus she cannot, in good conscience, give the injection. The other nurses resent interrupting their busy schedules to "cover" for Nurse Howard. Dr. Jones regards her refusal as a potentially serious form of disobedience.

One night, Nurse Howard is the only R.N. on duty. Mrs. Barnes has been very restless, and unable to sleep, even though she received her medication. In obvious discomfort, Mrs. Barnes presses the call button and asks for more medication. Her daughter pleads with Nurse Howard to help her mother. Nurse Howard hesitates. She is the only person on the night shift who is legally qualified to give this injection; if she refuses, she will have to bother Dr. Jones with a late-night call and suffer the consequences.

Do nurses have the right to refuse medical orders or to ignore the wishes of the patient and family on grounds of conscience?

COMMENTARY

Ellen W. Bernal and Patricia S. Hoover

Alice Howard has made an appeal to conscience the basis for her ongoing refusal to administer the morphine. Such an appeal should be founded on a prior judgment of the rightness or wrongness of an action. The action, if

the physician-patient relationship becomes weakened just when a strengthened relationship is needed.

But who really is best equipped to make the DNR decision—the patient or the physician? In addition to patients' underlying right to make decisions about their own care, they have an innate sense of their own well-being that is often overlooked. After all, M.G. has lengthy firsthand experience of the symptoms associated with metastatic breast cancer and is able to place those experiences in the perspective of her overall life achievements and expectations. Her fear of death may alternately be considered a will to live that could provide the wherewithal to sustain life longer than expected. Such attitudes can be driven by personal goals unknown to the physician—such as the need to support a spouse or a close relative, or the need to survive an important event. Why should a physician impose his or her own standards on the personal aspirations of the patient?

Physicians have been described as the appropriate decision makers because of their abilities to understand the extent of illness, the limitations of therapy, and the predictions about outcomes. But these abilities are not absolute. Prognosis determinations cannot be made with enough accuracy to warrant the physician assuming the dominant role in decision making. In the case of M.G., the gloom associated with the unrelenting nature of her illness might divert attention from potentially treatable and reversible causes of her symptoms, such as unrecognized infection, untapped fluid accumulations, and unopened airway obstructions.

Moreover, if the physician is right and all other therapeutic efforts are destined to fail, survival should be brief even if intubation and other resuscitation efforts are initiated. What then is the harm of attempting resuscitation in this setting? True, the patient may suffer more, the processes of dying will be lengthened, and the patient's agony may be prolonged rather than alleviated. But the patient is the best judge of what hardships can be endured and is often still capable of changing his or her decision about life-prolonging measures even after they have been initiated. By identifying an appropriate surrogate who is aware of the patient's attitudes toward therapeutic interventions, and by completing appropriate advance directives this patient's attitudes can be expressed even after her capacity to make decisions is lost.

There is also the harm that futile efforts to sustain M.G.'s life may mean that such efforts cannot be made available to a "more deserving patient." But such issues should not be subject to the individual whims of one attending physician and that physician's approach to the management of an individual patient. Rather, issues regarding the most appropriate utilization of limited resources should be reached through specific policy development, subject to review and scrutiny by appropriate supervisory bodies.

In the end these arguments substantiate the patient's right to prevail in the decision over whether to be resuscitated. In this case, protecting M.G.'s right to self-determination is paramount.

- greater good
- promote patient health
- informed consent
- confidentiality

PRIVACY AND CONFIDENTIALITY

trust v. truth + confidentiality

dist. = ethical permissibility (e.g. to warn) + duty - if doc may harm 3rd party, then a balance or interests (+ case protected from liability) - **TO**

AIDS and a Duty to Protect

- is immediate warning only option?

Mr. B., age twenty-eight, reported to the community health center of a large city teaching hospital for counseling after being confidentially informed that his blood test was positive for antibodies to the Human Immunodeficiency Virus (HIV), the virus that causes AIDS. The patient had no symptoms.

Dr. T. informed Mr. B. that although he did not have AIDS, there was between a five and thirty-five percent probability that he would develop the disease within the next five years. He was also told that he could probably infect others through sexual contact, by sharing needles, or by donating blood and blood products. He was counseled not to donate blood, and to engage in "safe sex," that is, sex that does not involve the exchange of bodily fluids such as semen.

Mr. B. then revealed that he was bisexual, and that he believed that he had contracted the infection during one of his homosexual encounters. He also said that he was engaged. Dr. T. advised him to inform his fiancée of his diagnosis. But Mr. B. refused to do so, saying that it would ruin his marriage plans.

Should Dr. T. inform the fiancée of Mr. B.'s test results, or should he protect the confidentiality of the therapeutic relationship?

NOTE: returned fear (+ limits to) do-h/patient confidentiality - COMMENTARY communication for treatment to enable Morton E. Winston treatment leans toward self

Dr. T. must weigh his duty to safeguard confidential information against a duty to protect his patient's fiancée, and any children the couple might conceive, from possible harm caused by Mr. B.'s infection.

The American College of Physicians Ethics Manual (1984) states that "the physician shall keep secret all that he knows about the patient and release no information without the patient's consent, unless required by the law or unless resulting harm to others outweighs his duty to his patient." The laws of most states require reporting of cases of sexually transmitted diseases such as syphilis, gonorrhea, and hepatitis B, to public health authorities.

At present, AIDS is a reportable disease in all states. However, only a few states, Colorado and Montana among them, presently require confidential reporting of persons who test positive for antibodies to HIV.

In this case, however, the relevant ethical question is not whether the physician should report the patient as being seropositive to public health authorities, but whether Dr. T. should warn his patient's fiancée that she may be at risk of developing AIDS.

Because the law is presently unclear regarding cases of this kind, physicians are exposed to uncertain legal risks; they may be sued by patients for wrongful disclosure and personal suffering that might result from such disclosure if they breach confidentiality; they may also be sued by their patient's sexual partners if they knowingly fail to protect them from preventable harm or risk of infection from their patient's illness.

* In 1976 in the case of Tarasoff v. Regents of the University of California, the California Supreme Court ruled that therapists who know or should know that a patient poses a violent threat to an identifiable third party have an obligation to take reasonable steps to protect that person. It also noted that "a doctor is liable to persons infected by his patient if he negligently fails to diagnose a contagious disease, or having diagnosed the illness, fails to warn members of the patient's family." AIDS (and all STDs) are limited (not casual)

However, the medical risks involved in the present case are different from those in diseases spread by casual, that is, nonsexual contact. Not all seropositive persons are viremic, that is, known to be producing virus, and some might not be infectious. There is evidence that male-to-female transmission of HIV occurs, but the efficiency of such transmission is unknown, though it may be high in some settings. Finally, the outcome of infection with HIV is not predictable with confidence, and not all infected persons will develop full-blown AIDS. These risks may vary for persons in different age, sex, and other groups, and our medical understanding of this disease is undergoing rapid change. These uncertainties argue strongly against instituting legal requirements mandating contact tracing for persons who have tested seropositive to HIV. The exceptional cases, such as this one, where patients refuse voluntarily to disclose their diagnosis to their sexual partners, are best handled on a case-by-case basis.

But then physicians must weigh carefully their responsibility to protect confidentiality against their duty to protect others who might be placed at risk by their patients' illnesses. While physicians should violate their prima facie obligations to protect confidentiality only with the greatest reluctance, it is morally permissible, and may sometimes be obligatory, for physicians to do so.

* The Tarasoff decision is often incorrectly interpreted as creating a "duty to warn." In fact, it creates a duty to protect potential victims of violence that can be discharged in various ways. If a physician determines that a patient's illness poses a significant risk to others, he could have him arrested for being a danger to public health, or move to have him civilly committed. In either of these cases, the damage done to the patient's rights and civil liberties would be considerable. In the present case, such extreme measures would be unjustified. In general, the duty to protect should be discharged in the way that is least invasive of the patient's rights while still effectively serving to protect potential victims from harm and significant risk.

Dr. T. could best discharge his duty to protect by persuading Mr. B. to reveal his diagnosis to his fiancée himself, and by offering serologic testing and counseling to her through his patient. Given contemporary sexual mores, it

is possible that the patient's fiancée may have already been exposed to the infection; she should still be informed of her risk of exposure, offered testing, and counseling, particularly concerning the risk of infecting any children she might conceive. Since the patient's fiancée is presumably not aware that she is a member of a high-risk group, it is unlikely that she would suspect that she may have been exposed.

If Mr. B. will not agree to voluntary disclosure, Dr. T. must seriously consider revealing the information himself. He should first discuss the case with appropriate legal, public health, and perhaps ethical authorities. If, after such consultation, he determines that the risk to his patient's fiancée is significant, and if all other means of persuading the patient to accept his moral responsibility have failed, then Dr. T. should attempt to contact her, either directly or through public health authorities.

COMMENTARY

Sheldon H. Landesman

learn toward don't tell

The question posed in the case is whether a physician is obligated, that is, has a legal or ethical duty to inform the sexual partner of an HIV-positive man that she may be at risk of acquiring AIDS through intercourse with him. Such a duty would appear to violate the principle of patient-physician confidentiality.

Medical confidentiality, however, has never been sacrosanct. The physician has always had the option of not maintaining patient-doctor confidentiality. Confidentiality can be breached when the patient's life is at stake and, in certain clear-cut situations, for society's benefit. The requirement to report communicable diseases and gunshot wounds, as well as suspected cases of child abuse, are clearly violations of confidentiality that are legally mandated and socially sanctioned.

The question can best be answered by looking at the broad societal problems associated with HIV infection. A central aspect in controlling the epidemic is counseling and testing the 1.5 to 2 million infected individuals in the U.S. Mandatory testing of the entire population is a logistically impossible and ethically unacceptable way of reaching infected persons. Encouragement of voluntary, confidential counseling and testing is more acceptable. The expectation is that many, if not most, people who discover they are infected will behave appropriately by informing their partners and practicing safer sex.

Any legally or socially sanctioned act that breaches confidentiality or imposes additional burdens (such as job loss or cancellation of insurance) acts as a disincentive to voluntary testing. Thus if all physicians were legally required to report HIV-positive persons to a health department or to inform sexual partners at risk from the HIV-positive person, no one would come forward for testing. This is especially true if the physician is known to treat many patients with AIDS and HIV infection. The public knowledge that such

* utilitarian concern

a physician has violated confidentiality would result (indeed, has resulted in several cases) in a sharp decline of potentially infected persons seeking counseling and testing. Consequently, a growing number of persons would remain ignorant of their infectiousness as would their sex partners.

Furthermore, which sexual partners might the physician inform? The spouse, the current girlfriend, the old boyfriend, the sexual partners not yet identified? As a general rule physicians should not be legally required to breach the confidentiality of an HIV-infected person for two reasons: it is ultimately counterproductive to the broader goal of encouraging voluntary testing and it is difficult to implement fairly.

The price of such a policy is high. The woman discussed in this case may pay the price; her future infection might have been prevented. For a Dr. T. to sit back and let such a scenario be played out is a painful, difficult thing to do. But his discomfort and the woman's infection may be the cost that society pays if it wishes to implement public health measures to minimize the spread of the virus.

Dr. T. does have room to maneuver. He can strongly urge Mr. B. to inform his fiancée, he can act as an information broker and make himself available to counsel the patient and the partner, or he can work with Mr. B. over weeks or months and gradually move him to a more reasonable position.

If all else fails, Dr. T. must review his own situation: he always has the option of informing the fiancée, although he should not do so without telling his patient of his intentions. If the physician is heavily involved with this epidemic; if he counsels, tests and treats many such patients, then violating confidentiality and informing the fiancée may ultimately result in more infected individuals. The breach of confidentiality will undoubtedly discourage others from being counseled and tested. If he does not have an "AIDS practice," it is easier to justify the violation of confidentiality.

The courts are the ultimate arbiter of the presence or absence of a legal duty to protect a sex partner from infection. In the absence of a clear legal mandate, the difficult ethical dilemma is one of balancing long-term societal benefits against short-term benefit to an individual. Although it is a difficult decision, and there may be exceptions to the rule, maintaining the patient's confidentiality ought to be the first principle.

11

A Duty to Warn, an Uncertain Danger

Ms. L., a twenty-eight-year-old, unmarried woman, is admitted to General Hospital to deliver her first child. In the past, she has been treated for pyromania and schizophrenia (paranoid type), and since the age of eighteen she has spent a total of five and a half years in a state mental hospital or in the inpatient unit of the local community mental health center in the suburban

community where she lives. She has also been arrested for arson on three occasions. Each arrest led to a court referral for psychiatric care.

Mrs. D., the social worker on the Ob-Gyn service at General Hospital, is familiar with Ms. L.'s psychiatric history and arrest record because she was formerly employed by the community mental health center where Ms. L. had been a patient. During a pre-delivery conversation with Ms. L. about her plans, Mrs. D. discovers that Ms. L. has no current residence and spent the previous year drifting from shelter to shelter. Ms. L. informs Mrs. D. that after her baby's birth she is planning to move in temporarily with a local rabbi and his family, who occasionally share their home with people in dire straits.

Mrs. D. immediately begins to wonder about warning the rabbi, Rabbi P., about the possible danger to him, his wife, and young children. As a member of Rabbi P.'s congregation, Mrs. D. is aware that, on occasion, he opens his home to transients. She is very concerned about the welfare of Rabbi P.'s family, given Ms. L.'s documented history of arson. The next day, Mrs. D. asks Ms. L. for permission to talk with Rabbi P. about her housing needs and about the difficulties she has experienced over the years. Ms. L. refuses permission for such disclosures.

Is Mrs. D. obliged to warn Rabbi P. about Ms. L. and her history, despite Ms. L.'s refusal to consent? Is it relevant that Mrs. D. came upon the confidential information about Ms. L. serendipitously, as a result of her previous employment in the local community mental health center?

COMMENTARY

Frederic G. Reamer

The commitment to confidentiality in the various health and mental health professions is deep-seated. Codes of ethics routinely cite the professional's obligation to hold in confidence information that a client shares. The Code of Ethics of the National Association of Social Workers—which is pertinent to Mrs. D.'s predicament—is representative: "The social worker should respect the privacy of clients and hold in confidence all information obtained in the course of professional service."

Difficulties arise, of course, when there appear to be good reasons for revealing confidential information against a client's wishes. The circumstances surrounding Ms. L. are typical in this respect, and every profession can produce similar stories. Understandably, confusion exists about the circumstances that warrant a breach of confidentiality, especially when a threat to a third party is involved. Though every professional knows that there must be limits to guarantees of confidentiality, there is no consensus about where the line should be drawn.

Debates about professionals' duty to warn generally address several often conflicting rights and obligations: the client's right to privacy; the professional's duty to protect the client's interests, along with those of the general public; and the professional's right to avoid being held liable. Based on these considerations, a good case can be made that Mrs. D. has a duty to warn Rabbi P. and his family about Ms. L.'s history and, thus, has a right to reveal

Q: validity of fertility treatment itself - control limitations on nature - if that ok. why not selective abortion - limits of control? - if we control having kids, why not control not having them? 18

* Selective Termination of Pregnancy

Ms. Q. is a thirty-year-old woman who is pregnant for the first time, having spent several years in a local infertility program. She had been treated previously with clomiphene citrate, a fertility drug that increases the incidence of multiple births among those who subsequently become pregnant from 1 percent to 8 percent. Dr. G., the physician who prescribed the drug, had indicated to the patient that its use involved "some risk of multiple gestation."

At nine weeks gestation, ultrasound reveals the presence of triplets. After discussion with her husband, Ms. Q. asks Dr. G. to terminate two of the fetuses. She says she really wants to have a child and "be a good mother," but doesn't feel capable of caring for more than one child at a time. Even though all three fetuses appear healthy, her preference is to abort all rather than have triplets.

A technique similar to amniocentesis (in which the uterine cavity is entered) has been used to terminate selectively a defective fetus, when a serious fetal anomaly, such as Down syndrome, occurs in a multiple gestation. This technique could be used to terminate two of the triplets, but it entails an incremental risk of miscarriage. Legally, Dr. G. could: (1) terminate the pregnancy through a standard method of abortion; (2) selectively terminate the gestation of two of the triplets; (3) refuse to terminate the pregnancy, with transfer of care to a physician who is willing to do so. Should Dr. G. acquiesce in Ms. Q.'s request? Is this request morally valid?

COMMENTARY

Angela R. Holder

The central question in this case is, "What are the limits of a physician's duty to do what the patient wants?" No physician is legally obliged to provide treatment he or she deems unwise, dangerous, or not indicated simply because a patient wants it. Dr. Q. is no more required to abort one, some, or all of Ms. Q.'s fetuses than a physician is to give human growth hormone to a normal-sized child whose parents want a basketball star. The legal doctrine of informed consent means that a patient has the right to choose among reasonable medical alternatives; it does not mean that the physician must perform the chosen procedure if he or she thinks it is ill-advised. In case of necessary medical care, the physician may have a duty to refer the patient to someone who will comply with the patient's requests, but the condition of "necessary" would not apply to Ms. Q.'s situation.

Under normal circumstances, Ms. Q. would have no trouble finding a physician who would perform a standard abortion, and, at this stage in the pregnancy, she has every legal right to decide to have one. (Since family fi-

nances have apparently presented no impediment to several years of infertility treatment, presumably she can afford this procedure.)

However, the procedure for selective abortion presents about a 45 percent risk of loss of all fetuses. There is also a risk that triplets will be sufficiently premature to have serious difficulties—many are born at thirty weeks gestation. While some obstetricians might be willing to abort one fetus with a severe disorder, not many would agree to undertake a procedure still in its developmental stage only because a woman decided she was incapable of being a good mother to three children.

Ms. Q. had been in the infertility program for several years. That experience surely should have presented opportunity for adequate counseling about the possibility of multiple births, since they cannot be predicted or prevented when fertility drugs are used, and what such a possibility would mean in terms of expenditure of energy and finances. In advance of her pregnancy, Ms. Q. should have been able to think through for herself whether she could cope with this eventuality. Did she really want a baby, or was she in this program to satisfy the desires of other people—her husband, for example, or her parents who wanted a grandchild? Does she have any idea how much energy one baby requires? Several years of treatment should have provided Ms. Q. with better counseling, rather than leaving her in this dilemma, since it was a reasonably foreseeable result of doing what she wanted to do.

Dr. G. should really? arguably unethical? attempt to mobilize family and child care resources (including her husband, who presumably can learn to change diapers as well as she can) and facilitate contacts with mothers of triplets to find out how they cope with three children the same age. Perhaps Ms. Q. will discover that the situation is not as difficult as she assumes and continue the pregnancy.

As Oscar Wilde wrote, "In this world, there are only two tragedies. One is not getting what one wants, and the other is getting it."

COMMENTARY

Mary Sue Henifin

Unlike the "old woman who lived in a shoe, she had so many children she didn't know what to do," Ms. Q. has requested an available medical intervention as a solution. The question of whether Dr. G. should acquiesce in her request for partial termination of her multiple pregnancy is one that tests the limits of a physician's obligation to respect patient autonomy.

Self-determination and autonomy apply to a patient's "negative" right to refuse as well as her "positive" right to choose among beneficial procedures, yet these principles do not guarantee the right to demand nonbeneficial or harmful treatment. Before providing a requested treatment, the physician should determine whether the patient can define a recognizable problem

could she think through likelihood of success? if doc - it's certain that some patients will face this

but ethically?

legal?

legal.

of condition of risk of patient to reproductive decisions autonomy

doc is not

real

that medical treatment may benefit. If a requested treatment is beneficial, it should be among the options offered to the patient. ^{* conclusion}

In this case, triplet pregnancy presents many recognizable problems to which partial termination is one solution. Once a benefit can be identified, the pregnant woman is in the best position to weigh the alternatives. Each woman brings her own ethical principles to decisions about her pregnancy based on her own life circumstances.

In an ideal relationship, physician and patient share their mutual knowledge and perspectives until they arrive at an agreed upon course of treatment prior to commencing therapy. In the case of inducing ovulation with clomiphene citrate, the discussion should include the eightfold increase in the risks of multiple gestation and accompanying maternal and fetal complications, not merely the vague warning provided by Dr. G. that there is "some risk."

What information does Ms. Q. need to make an autonomous decision? First, the physician must present those options that can provide benefit and discuss their risks. Three options could benefit Ms. Q.: carrying the fetuses to term, complete abortion, or partial termination. A triplet pregnancy is by definition high risk, with stillbirth rates three times higher than for singleton pregnancy and perinatal mortality rates almost twenty times higher. Multiple gestation increases the strain on the pregnant woman's circulatory, renal, and endocrine systems, and she is more likely to suffer from hypertension, anemia, respiratory distress, preeclampsia, placenta previa, and placenta abrupta. about beyond birth

The fetuses are also at increased risk. The majority of multiple births are preterm; and intrauterine growth retardation is the rule, caused by placental insufficiency and crowding. Labor and delivery are particularly risky. Moreover, children born of multiple gestation have higher rates of congenital disabilities and development problems after birth.

Finally, multiple gestation severely disrupts the life of the pregnant woman and her family. Bedrest is usually prescribed beginning in the third trimester and lengthy hospital stays may be required for both mother and newborns. Depression and, in rare cases, suicide have been reported to accompany multiple births as families try to cope with the caretaking, social, and economic pressures. Although support groups exist, such as The Triplet Connection in California and Central New Jersey Mothers of Multiples, reproductive choice may be circumscribed by inadequate access to medical coverage, housing, child care, and other necessities.

Once risks have been identified, the physician should avoid paternalism and respect the patient's evaluation of her own unique circumstances. Just as it would be unethical for Dr. G. to pressure Ms. Q. to abort because of the known risks of multiple gestation, it would be wrong to try and pressure her to forgo partial termination because of alternative risks. Ms. Q.'s constitutionally protected right to privacy, including the right to make procreative decisions, supports her right to weigh the available options and their out-

* note Roe's permission of abortion restriction in 2nd term based on mother health risk

comes in selecting a course of treatment. Even when more accurate data are available on the relative risks of multiple gestation, abortion, and partial termination, privacy and procreative liberty must extend to protect the pregnant woman's choices. Dr. G. should either respect Ms. Q.'s decision or transfer her care to a competent physician who is willing to do so.

Ms. Q.'s case illustrates how the development of new reproductive techniques leads to technological imperatives: If a technology exists it will be used. The critical focus is usually on the morality of "consumer demand." A more direct approach would examine the moral responsibility of researchers who develop and promote new reproductive technologies like selective termination. - and fertility treatments themselves?

+ Illich: medical technology as Pinocchio's Box? (not an Illich figure btw)

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justifiably forced an investment of pain that was not agreed to. Of course, there are no easy answers. Physicians should not abandon patients when momentarily pain overwhelms them; physicians should seek to gain consent for therapy. But when the patient who is able to give free consent does not, the moral issue is over. A society that will allow persons to climb dangerous mountains or do daredevil stunts with cars has no consistent grounds for paternalistic intervention here. Further, unlike the case of the motorcyclist or the would-be slave, in this case one would force unchosen pain and suffering on another in the name of his best interests, but in circumstances where his best interests are far from clear. That is, even if such paternalistic intervention may be justifiable in some cases (an issue which is different from the paternalism of surrogate decision making, and which I will not contest at this point), it is dubious here, for the patient's choice is not a capricious risking of the basis of free action, but a deliberate choice to avoid considerable hardship. Further, it is a uniquely intimate choice concerning the quality of life: the amount of pain which is worth suffering for a goal. Moreover, it is, unlike the would-be slave's choice, a choice which affirms freedom on a substantial point—the quality of one's life.

In short, one must be willing, as a price for recognizing the freedom of others, to live with the consequences of that freedom: some persons will make choices that they would regret were they to live longer. But humans are not only free beings, but temporal beings, and the freedom that is actual is that of the present. Competent adults should be allowed to make tragic decisions, if nowhere else, at least concerning what quality of life justifies the pain and suffering of continued living. It is not medicine's responsibility to prevent tragedies by denying freedom, for that would be the greater tragedy.

Note: patient not harmed, ~~but~~ ^{may} (20% chance) become respirator-independent; contrast #28 (p.128)
 - Autonomy + technology: patient becomes powerless to control physically, ^{own destiny, thus thrusting responsibility on doc & family} 25

Family Wishes and Patient Autonomy

Ralph Watkins, a seventy-five-year-old married man, was admitted to the intensive care unit of a university hospital in acute respiratory distress. He was anxious but fully alert and gasping for help. A retired laborer, Mr. Watkins had been suffering from a chronic pulmonary disease for the past fifteen years. For the past five years he had become progressively debilitated. Prior to admission he had been confined to his home and depended on his wife for the most basic of care: without her assistance he could not dress or feed himself. He had been a fiercely independent man and still enjoyed ordering people around. His wife and married son were totally devoted to him.

The diagnosis was bilateral pneumonia, and Mr. Watkins was given antibiotics and put on a mechanical respirator with supplemental oxygen. Within two weeks the pneumonia was largely cleared and Sarah Radburn, his physi-

cian, began attempts to wean him from the respirator. Unfortunately, he had become "respirator-dependent" as a result of a combination of poor nutrition, possible new damage to his lungs, weakened respiratory muscles, and fear of breathing on his own. Despite a slow, cautious approach with much reassurance, the weaning attempts repeatedly failed. Mr. Watkins, short of breath and terrified, would demand to be placed back on the respirator.

Dr. Radburn rated the ultimate chance for successful weaning as "maybe 20 percent." The patient became more and more discouraged with his lack of progress and the frequent painful medical procedures (constant intravenous feeding, frequent needle punctures for arterial blood gases, suctioning, and so on). After three weeks of unsuccessful efforts, Mr. Watkins refused to cooperate with further attempts at weaning. His wife and son became concerned that he had given up the "will to live." They begged the medical staff to "do something to save him." Although he had become less communicative, he remained alert and aware and, in the opinion of the staff, was fully competent. He told Dr. Radburn he wanted the respirator disconnected. "I want to die," he said.

What is the physician's responsibility in this case? Should the physician honor the patient's request? If we assume the patient is legally competent to make medical decisions, on what basis, if any, can the physician refuse or postpone acting on the request to stop life support? How much weight should be given the family's wish to "save" the patient?

COMMENTARY

Stuart J. Youngner and David L. Jackson

This case illustrates the often confusing and conflicting responsibilities that confront physicians in today's modern, high-technology medical environment. To preserve life, relieve suffering, do no harm, and respect the autonomy of this alert, competent man is no simple task. If Mr. Watkins were comatose or delirious, he could be declared incompetent and the family or a court-appointed guardian would make the decision. Confronted with the realities in this case, however, one could "solve" the problem most simply by taking one of two courses—both of which, we feel, are wrong.

First, one could insist that Dr. Radburn's primary responsibility is to try for the 20 percent chance of saving his life. After all, the patient placed himself in her care, and she can dismiss his wish "to die" as irrational, although not incompetent, and press on. This course is unacceptable because it violates the patient's autonomy. It also ignores the great degree of suffering and the small chance of regaining a "meaningful" life.

Equally simplistic, and in our view unacceptable, would be to respond to his expressed wish to die by immediately disconnecting the respirator, while piously proclaiming respect for patient autonomy.

It is noteworthy that both these courses (relentlessly pursuing treatment or rigidly following the patient's request) allow the physician to avoid a time-consuming and potentially painful dialogue with the patient and fam-

ily. We suggest that before the respirator is disconnected and the irrevocable decision made to let the patient die, the physician must evaluate with the patient and family the following:

1. Does the wish "to die" represent a temporary depression in reaction to pain or a sleepless night? If the depression passes or is adequately treated, the patient may well retract the wish to die. Of course, depression may be a realistic and consistent response to a situation of great suffering and little hope.

2. The patient's request may be a reaction of fear based on misperception or misinformation. Before stopping treatment the physician should identify any fears underlying a refusal of treatment and explore their source with the patient. Fear may be appropriate to many situations, and a reasonable basis for refusing treatment.

3. In similar intensive care units, we have seen several cases in which patients have exhibited true ambivalence about stopping treatment. If adequate dialogue is not established, the physician may hear only that side of the ambivalence with which he or she agrees. Acting on such half-truths is hardly honoring the principle of patient autonomy.

4. A patient's request to have treatment stopped may be a symbolic attempt to regain control in a situation in which he has none. A critically ill, machine-dependent patient has little autonomy in the most mundane and basic aspects of his life such as sleeping, elimination, eating, and privacy. He is totally at the mercy of others. The request for termination of treatment may be a desperate effort by a helpless patient to get the attention of his family and caregivers and to assert his independence. Thoughtful investigation may discover alternative measures that restore the patient's sense of autonomy and with it a revival of the wish to pursue life vigorously.

5. An apparent clash between the wishes of the family and patient may identify underlying problems of communication between them. The physician must clarify with the family the meaning of their cry "to save" the patient. Are they acting out of guilt? Can they distinguish their own needs from those of the patient? A meeting with patient and family together may be the only means of clarifying the apparent disagreement. If the issue cannot be resolved the patient must have the ultimate input to the decision-making process. The physician's contract is with him and ultimately it is his fate being decided.

The possible interventions and evaluations we have suggested will postpone acting on a patient's request to stop treatment. In doing so we could be accused of "paternalism" and violating the patient's autonomy. However, as Eric Cassell (*Hastings Center Report*, December 1977, pp. 16-19) has pointed out, a sick person is not simply a well person with an illness appended. Life-threatening illness, dependence on machines, and the ensuing physical and psychological regression make the concept of autonomy much more difficult to apply. By postponing an irreversible decision until important issues can be clarified, physicians may not be violating the true autonomy of their pa-

ients. Reflex acquiescence to patients' wishes that treatment be stopped may be a way for physicians to avoid close dialogue with fellow beings in their hour of greatest need. If the dialogue is completed and the patient's wish to die remains, there is almost always time to withdraw life supports.

COMMENTARY

William Ruddick

In order to sharpen a single issue I shall assume that the courts, the hospital's regulations, and the physicians' professional and moral principles do allow patients in such circumstances to refuse life-saving treatment. Nevertheless in this case as sketched, Dr. Radburn should first explore the conflicting requests. Her first responsibility is to make sure that the patient's request expresses an informed, autonomous, and resolute desire to die and is not merely a show of "fierce independence."

Suppose that various inquiries convince the physician, staff, and consultants that the patient means what he says for reasons appropriate to his age, condition, character, and other circumstances. His pain is tolerable, but his increasing and irreversible debilitation and dependence are not. Even ordering people around has ceased to relieve his "burdensome" life. Despite his family's pleas, he wants to die—even if he can still be weaned from the respirator.

His wife and son want him kept alive, even if he cannot be weaned. They realize they have no legal means to prevent the physician's termination of treatment, but if the physician refuses the patient's request, they trust that he will be too weak to enlist legal aid (or to turn off his own respirator). For reasons of affection, shame, and "philosophy of life and death," they prefer his forced survival to his death by what they perceive as suicide.

These elaborations simplify the case:

1. The probability of weaning becomes irrelevant: the patient wants to die, even if weaned; his family wants him kept alive, even if respirator-dependent.

2. The direct conflict of their desires shows that the patient is not influenced by self-serving family suggestion or fear that he has become a resented burden.

3. Free of all other opposition to terminating treatment, the physician must base any refusal or further delay solely on the family's desire.

What then are the physician's professional and more general moral responsibilities? Should the family's desire, or considerations of their welfare, deter her from "honoring the patient's request"? I think not. The family are not her patient, nor the patient's proxies. Nor does his decision or welfare depend on their own. A physician often has a derivative responsibility for the welfare of family members who can provide a patient with hope, courage, nursing or financial aid, or legally required representation. But she has no

such derivative professional responsibility for the family's welfare here. Indeed, to the extent that she shares her patient's belief that he would be "better off dead" or would die better now than later, she must oppose those who would forcibly continue treatment. A family's welfare does not compete with, let alone overrule, a patient's welfare in a physician's deliberations. *(i.e., it's irrelevant)*

Though not professionally responsible for the family, Dr. Radburn is nonetheless responsible to them in at least two ways. Given their concern and past care for the patient, they are owed a thoughtful account of the decision to terminate treatment. Whether or not they are employing her, the physician must answer to them for the proposed course of action. Moreover, benevolence requires her to try to reconcile the family to her decision. If their religious principles cannot be interpreted to permit termination, she may only be able to prepare them for the patient's death. Even if the patient is being selfish in his distress, the physician should take concern for those he is (excusably?) ignoring and harming. And even if he is acting "within his rights," benevolence requires the physician to moderate the avoidable suffering produced. The demands of virtue cannot block the exercise of rights (otherwise rights would lose their force), but they can delimit the manner in which others facilitate the exercise of those rights.

In summary, the physician has two grounds for delaying, but none (as the case is elaborated) for denying the patient's request. Time is needed for: (1) making sure that the patient's request expresses a deliberate, resolute desire; and (2) trying to lessen the suffering of the family whose plea she professionally should reject but morally must respond to with compassionate attention. The first delay involves a paternalistic defense of a patient against undue influence by haste, pain, drugs, or others whose desires and welfare are not an integral part of the patient's own concerns. (This "subject paternalism" appeals to a patient's characteristic desires, not to his or her "best interests.") The second delay is justified by the coordination of rights with virtues that limit the manner of their exercise, especially with regard to the cooperation of the physician and the suffering of the family. Like any right to life, any right to die must be located in a context of virtues, as well as of other rights. Contrary to current slogans, people do not die alone.

26

"If I Have AIDS, Then Let Me Die Now!"

Dr. Lois Dorsey, a psychiatry resident, was paged by an intern from the Medical Intensive Care Unit (MICU) for an emergency psychiatric consultation. Gary Davidson, a twenty-eight-year-old gay man, had been hospitalized eleven days before for a first episode of *Pneumocystis carinii* pneumonia

(PCP). One week earlier he had been told that the presumptive diagnosis for his illness was Acquired Immunodeficiency Syndrome (AIDS).

On the day Dr. Dorsey was called, the medical team discussed with Mr. Davidson the need for a Swann-Ganz catheter, which would be inserted in his pulmonary artery. Mr. Davidson refused permission for placement of the catheter, and requested that medical treatment be stopped. "Take the tubes away and let me die with dignity," he declared.

The medical team discussed in detail with Mr. Davidson, his lover, and his parents and sister his clinical status and prognosis; Mr. Davidson had, they believed, a 50 percent chance of surviving the current illness. However, people with AIDS rarely survive more than two years* and Mr. Davidson could expect several bouts of severe illness during his remaining lifespan. They also pointed out that rapid advances were being made in understanding the pathophysiology of AIDS and offered the prospect for a future treatment as a result of current research efforts.

With the support of his lover and family, Mr. Davidson continued to insist on cessation of treatment, citing as his reasons "quality of life" and the "right to die with dignity." In the presence of witnesses he signed a living will and statement of competency. The legal formalities were carried out; however, for "legal reasons" and "completeness," before complying with the patient's request, the medical team was waiting for a psychiatric assessment.

Dr. Dorsey reviewed Mr. Davidson's records and interviewed him. Mr. Davidson reaffirmed his belief that quality of life was more important than quantity of life and that he wished to die with dignity. He admitted that he was feeling pain, fear, loss of control, extreme discomfort on the respirator, and sleeplessness. He added that he was distressed by his inability to eat (on the respirator). When Dr. Dorsey asked how he might feel should he recover from the pneumonia, the patient noted that he knew he had AIDS and that he would die within one or two years. Therefore, he said, he did not deserve to take up a bed in the hospital and continue to receive medical treatment that could better benefit another patient.

The patient had no psychiatric history and had never attempted suicide. He had never had any personal experience with death or dying among family or friends. He could not speak because of the respirator tubes but he communicated by writing notes and nodding his head. He was alert, not disoriented, wrote clearly and logically, and initiated his own statements and topics for the interview. He was not tearful but appeared anxious. In his own eyes he did not want to commit suicide but wanted to be allowed to die.

Dr. Dorsey concluded that the patient showed no evidence of confusion, psychosis, or delusional thinking, but that he did show symptoms consistent with depression, probably secondary to his underlying medical condition.

Mr. Davidson, then, was legally competent, understood the consequences of his decision to refuse treatment, and had the support of those closest to him. Yet, because of his age and depression, the availability of treatment for his current illness, and the possibility that some treatment for AIDS may become available within the next few years, Dr. Dorsey hesitated. Should Mr. Davidson's treatment be stopped as he wished?

*Advances in therapy in recent years have led to significantly improved survival rates for most patients.

rently there, Dr. D. is left to proceed on his own unexplored and unverified interpretation. He must treat because he failed to talk to his patient.

The lesson of the case is clear: it is critical that the medical team be alert to ambiguities in advance directives. The pressures of emergency medicine sometimes make this difficult, but in this case there was time and opportunity, and the physician involved was informed and had relevant experience, making the failure to have the discussion inexcusable. The case points up the fact that advance directives are sometimes idiosyncratic. They are intended as a reflection of personal values, not a rote rejection of some kinds of life support. They require inquiry on the part of the physician to make certain that the physician fully understands the patient's wishes and is prepared to act in accordance with those wishes. Had Dr. D. but asked what Mr. R. meant by "under any circumstances," or even why he had chosen to express his wishes in that way, he would have spared Mr. R. the prospect of having his actual wishes ignored.

- beneficence v. autonomy? paternalism? "protect life" = negate autonomy
- ought a doctor impose a feeding tube on an unwilling patient (who is permanently incapable of restoring function, except opelid)
or prolong physical function?
"do no harm"?

28

ordinary care v. extraordinary - feed ventilator + feeding tube are
"No Feeding Tubes for Me!" permanent - not designed
to restore function (no prospect of returned function)

Pauline Randall, a sixty-five-year-old married woman with three adult children, has been suffering from amyotrophic lateral sclerosis (ALS) for several years. Her neurological condition has deteriorated so that she can no longer control any voluntary muscles. Confined to bed in a nursing home in a small midwestern American city and breathing with the aid of a respirator, she communicates through the electronic monitor that responds to eyelid blinks. She can "write" words and brief sentences in this way.

Mrs. Randall understands that her condition cannot be treated and that it will inevitably lead to her death. But she has been an active participant in her health care and has been determined to continue functioning as long as possible.

Her physician, Dr. Samuels, believes that she is not receiving adequate nutrition and that the time has come to insert a nasogastric feeding tube. When he proposes this procedure to her, she blinks quickly, "No more!" He asks, "Do you understand that you will die slowly of starvation if we do not insert this feeding tube?" "Yes," she blinks, "No more."

When Mrs. Randall's family, which has been close and supportive throughout her illness, learns of her opposition, they have divided opinions. Her husband believes that her wishes should be respected, but two of their three children are convinced that her life should be prolonged. The nursing staff believes that she should not be made to suffer any longer.

There is no question that Mrs. Randall is legally competent, that is, that she understands the procedure being proposed and the consequences of refusal.

Re: As
Spinal -
here
terminal
patient!
+ need of
respirator
+ now tube
there 20%
chance of
wearing
from
respirator

note: whole brain is alive - ventilator not into brain but muscle - can
have lower brain into upper but not upper into lower - upper
brain much more fragile

Should her refusal of the feeding tube be honored, even though it will lead to her death?

COMMENTARY

Richard H. Nicholson

concl.: respect patient wish based on "responsibility
body of medical opinion" (i.e. not patient
wish as such)

In 1860, the English poet, Arthur Clough, wrote "The Latest Decalogue," only one couplet of which is usually remembered nowadays:

Thou shalt not kill; but needst not strive
Officially to keep alive.

Today those lines are often quoted in the United Kingdom as summing up a proper attitude to terminal care. Repeated use out of context, however — starting with Bernard Shaw in "The Doctor's Dilemma" — has hidden the lines' origin in parody. Clough's poem went on:

Do not adultery commit;
Advantage rarely comes of it;
Thou shalt not steal; an idle feat,
When it's so lucrative to cheat.

Such an error is not untypical of the deceptions and misunderstandings that surround the care of patients with terminal, or inevitably fatal, illnesses. Mrs. Randall understands that her neurological deterioration will lead inevitably to death; yet one wonders whether Dr. Samuels has accepted that she is a dying patient. After all, at a slightly earlier stage of her illness, he acted in a way that would almost never happen in the United Kingdom. He started to aid her breathing with a respirator.

Since she can no longer control any voluntary muscles, such respiratory assistance, to be effective, would almost certainly be intermittent positive pressure respiration (IPPR), probably administered via tracheostomy. The normal way in which ALS patients die, when not attached to a ventilator, is by suddenly, and usually unexpectedly, stopping breathing; at autopsy it is uncommon to find any reason why death happened at that particular point. Artificial respiration is likely to prevent this mode of death, and was therefore a major intervention in Mrs. Randall's dying.

Cynics might suggest that the only reason why a patient like Mrs. Randall would not be artificially ventilated in the United Kingdom is that the National Health Service cannot afford enough ventilators. In fact for many years U.K. doctors have assessed the value of such interventions in terms of the probable quality of life as well as the probable quantity. In the 1936 House of Lords debate on the Voluntary Euthanasia (Legalisation) Bill, Lord

vk

Dawson, the royal physician recently revealed to have eased King George V's passing with morphine and cocaine, said:

If one goes back fifty years . . . it was an accepted tradition that it was the duty of the medical man to continue the struggle for life right up to the end. With time that has changed. There has gradually crept into medical opinion, as there has crept into lay opinion, the feeling that one should make the act of dying more gentle and more peaceful even if it does involve curtailment of the length of life.

When you pass . . . to lives which are burdened by incurable disease, and where the gap between that stage of illness and death becomes wider, it may be fully admitted that the difficulty is greater, yet when the patient is carrying a great load of suffering, our first thoughts should be the assuagement of pain even if it does involve the shortening of life.

Pain and comfort will in fact be important considerations in Mrs. Randall's case. Although she cannot move at all, her sensation is probably intact. Without extremely skilled and, above all, experienced nursing care she will frequently be very uncomfortable. Such experience will not be available in a small city where there is probably no more than a single case of motor neuron disease each year. Thus it will be important for her to have very regular small doses of morphine to take away the feeling of pain and discomfort; morphine will also take away the feeling of thirst or hunger.

Concern for the quality of Mrs. Randall's dying and the provision of appropriate care mean that she is most unlikely to have any sensation of hunger or thirst. Starvation therefore holds no fears for her and, with her intellect intact, she can decide to refuse the nasogastric tube. In U.K. hospices, where such appropriate care is available, it is neither the physician in charge nor the patient who raises the possibility of a nasogastric feeding tube: it is usually the intern or resident. Once the possibility has been raised it will be discussed widely among the doctors and nurses, within the family, between the doctors and the patient, and between the doctors and the family. The conclusion is nearly always that a feeding tube should not be used. This accords with the principle that a doctor is under no moral obligation to do to a patient that which is of no benefit to the patient. Many people in the U.K. would regard as a refined form of cruelty any technical intervention to prolong the life of a patient whose mind and sensation are working, but who is incapable of any voluntary action and whose ability to communicate is minimal.

In the rare event that it is not possible to reach accord among the patient, doctors, and family, the outcome may be different. In Mrs. Randall's case, she and her husband agree, and no doctor would go against their combined wishes. If only Mrs. Randall refused the feeding tube, while her husband and family wanted it inserted, the likely outcome would be whatever the doctor thought best: and that would most likely be to withhold the tube.

If Mrs. Randall and her husband and family all still wanted a feeding tube inserted, then it would be inserted, regardless of the doctor's opinion.

Such a case has never been to court in the U.K. If a court were ever called on to decide, it would do so under English common law according to whatever practice a responsible body of medical opinion felt to be appropriate. In other words, if Mrs. Randall refused the tube, the court would uphold that decision, since the majority of experienced doctors in this field would not wish to feed her.

In summary, this case could never have taken the course it did if it had occurred in the U.K. Ventilator support would not have been offered, and a senior physician would not have proposed inserting a nasogastric tube. Both, in the circumstances, would have been regarded as extraordinary, rather than ordinary, means of care, therefore carrying no obligation that they be used. All efforts would be concentrated instead on ensuring that routine care kept Mrs. Randall as comfortable as possible, so that the burden of her inevitable dying was kept to a minimum for her and her family. Such care would include very careful positioning, drug treatments such as hyoscine to reduce salivation when swallowing became difficult, mouth care to prevent thrush, and attention to her bowels to avoid fecal impaction.

Why such cases can and do occur in the United States is sometimes difficult for America's transatlantic cousins to understand. Can it really be explained just in terms of a desire to avoid malpractice litigation? Or does it reflect the essential Puritanism of American society, with its tendency both to demand masochism, and to reject doctrines, such as that of ordinary and extraordinary means, which sound too Catholic in origin?

influence of cultural relativism

COMMENTARY

Hans-Georg Koch and Tatjana Ulshoefer

In the Federal Republic of Germany (FRG), the case of Pauline Randall would raise numerous legal and ethical problems, in part because the discussion about euthanasia is burdened by historical experience. The so-called "extermination of unworthy life" during the Third Reich still affects the current debate.

In the FRG one distinguishes among three kinds of euthanasia. What is called "passive euthanasia" means the withdrawal or nonapplication of life-supporting measures. The term "indirect euthanasia" describes measures with the primary purpose of minimizing the suffering of a patient, even if this implies hastening the time of death. "Active euthanasia" means all measures that actively and deliberately induce death, such as the administration of drugs with the intention of terminating life, regardless of motive.

There is a consensus that this last kind of "euthanasia" should be punishable by law. This applies even if it is carried out in accordance with the sincere

FRG

and expressed wishes of the patient. (The applicable law, section 216 of the criminal code, states that killing on demand constitutes a punishable offense.)

Another preliminary remark seems in order. The discussion about euthanasia in the FRG is largely overshadowed by the debate about suicide. Most of the euthanasia cases that have reached the courts involve patients who had previously attempted to commit suicide. The Supreme Court, in several widely criticized decisions, has stated that suicide is an ethically reprehensible action. These decisions influence the evaluation of the obligations of a physician who attends a would-be suicide. In accordance with these decisions handed down by the court, the physician is liable to be prosecuted for homicide by negligence if he encounters an unconscious would-be suicide victim in a life-threatening situation and fails to administer all required and reasonable aid.

On the other hand, assisting a person determined to commit suicide is not punishable per se, nor is it regarded as suicide if a patient, being aware of his or her situation, refuses life-preserving treatment and accepts his or her inevitable death. This can, in a particular case, lead to conflicting evaluations.

A case comparable to that of Pauline Randall's has as yet, so far as we can determine, not come before an FRG court. Nevertheless, it is generally accepted that a patient has the right to refuse even part of an envisioned course of treatment—such as a specific surgical procedure. Furthermore, in medical practice the use of respirators as well as the insertion of nasogastric feeding tubes are both considered ordinary treatment. Such a wish expressed by a patient has to be respected by the physician, even if it might threaten the life of the patient and is therefore seen by the physician as irrational.

This obligation to respect the wishes of the patient results from the constitutionally guaranteed right of self-determination as well as the right to protect oneself against physical violation. This applies even in cases where a (temporary) physical violation might be medically indicated in order to save the patient from a life-threatening illness. A surgical procedure undertaken without the consent of the patient constitutes an illegal and punishable act.

This obligation to respect the wishes of the patient, however, does not obviate the duty of the physician to counsel the patient and to recommend measures which may be medically indicated. Likewise, it does not release the physician from the duty to render medical and nursing care to the patient, as well as measures that alleviate suffering, as long as the patient so desires.

Although the problem of euthanasia has been discussed in the FRG for a considerable time, there are still no clear legal provisions governing a physician's actions when a patient's life approaches its end. In view of this legal void, various medical organizations have drawn up guidelines for physicians facing a patient's approaching death.

In 1986, an interdisciplinary working group (composed of professors of criminal law and medicine as well as their assistants) produced an "Alternative Draft Bill Concerning Euthanasia" (published by G. Thieme Verlag, Stuttgart and New York). Furthermore, the subject was discussed last year by

the criminal law committee of the fifty-sixth convention of the German Lawyers Association.

Given this situation, procedures in the FRG in a case similar to that of Pauline Randall's would presently be as follows:

The case of Pauline Randall would be regarded as falling into the category of "passive euthanasia," meaning the withdrawal of life-prolonging measures. The patient is fully able to express her informed wishes. In such cases, the patient's wishes are decisive, because a physician's duty is to protect life, not to force patients to continue to live against their wishes.

The positions taken by the patient's next of kin, and even more so those of the nursing staff, are irrelevant, as long as it can be assumed that the patient has made an informed decision. Differing opinions of, for instance, the patient's spouse or children do not have to be taken into consideration.

The attending physician would have to respect Mrs. Randall's wishes even if he has arrived at a different conclusion, which he regards as "medically reasonable." He is obliged, however, to counsel the patient and to recommend the procedures he considers reasonable.

Although the physician has to respect Mrs. Randall's right to reject feeding by nasal tube, nevertheless he might continue the other elements of medical care, including all nursing care.

In a somewhat different case Peter Noll, a Swiss professor of criminal law widely known in Germany, acted similarly to Mrs. Randall. When confronted with a diagnosis of cancer of the bladder, he decided against the mutilating surgical procedure recommended by his physicians, although he had a good chance to be cured. In a diary, Professor Noll recorded his thoughts and feelings for posterity. He wrote: "The will to live should not be so strong that one passively endures all pains of life-extending measures" (Peter Noll, *Diktate über Sterben und Tod*, Zurich: Pendo Verlag, 1984).

COMMENTARY

Ren-Zong Qiu

- patient autonomy should rule.
- cultural issue of filial piety a strong influence on family to preserve life regardless

A case like Pauline Randall's is not rare in China, even though it is a country socially and culturally quite different from the United States. In December 1986, a session of the Beijing Colloquia on Medical Ethics (a group comprised of interested professionals in ethics, medicine, and health care administration that meets bimonthly to address topics in biomedical ethics) discussed three cases of pain-ridden dying cancer patients who refused to accept treatment, in addition to three other cases of patients who were irreversibly comatose.

One of these dying cancer patients committed suicide as a result of the physician's refusal to withdraw treatment. The second attempted suicide after a similar denial but failed, whereupon a physician approved his request

and he died peacefully. The third is still alive; he thought about suicide after his physician refused to withdraw treatment, but he has not attempted it.

Cases of this sort occur mainly in the middle-sized or big cities and other developed areas where a number of modern hospitals are located. The situation does not occur in the 10 percent of villages where people still live in abject poverty without access to health care and even without enough food and clothing, or in other underdeveloped areas.

Public officers and medical professionals are divided on the question of whether the treatment refusal of a patient like Mrs. Randall should be accepted. A survey conducted by investigators from the Central China University of Science and Technology, the Beijing Union Medical College, the Capital Medical College, and the College of Traditional Medicine in the spring of 1986 found that among 170 respondents including laymen and professionals, 39.4 percent approved of active euthanasia for a pain-ridden dying cancer patient; 31.8 percent approved of treating her with all-out efforts; 16.5 percent advocated ordinary care and food; 10 percent wanted to withdraw all treatments and food and let her die; and 2.3 percent were undecided. So far technology for electronic communication, such as was available to Mrs. Randall, is not available in China, and generally respirators and feeding tubes are classified as extraordinary care.

Although the percentage advocating passive or active euthanasia was rather high (49.4 percent), I doubt that the advocates would definitely follow through in practice. One of my friends was terminally ill with intractable pain and refused further treatment. Both the attending physician and her two children agreed that the treatment would only prolong her suffering and death. But nobody took the move. Why? The cultural climate bound them hand and foot.

The Confucian tradition is deep-rooted in China. There are twenty-four popular models of behavior of the dutiful son from various periods in Chinese history. Some of them made every effort to save their parents' lives, and they still serve as examples of filial piety. According to the Confucian tradition, if the child agreed to the parent's refusal of treatment, he or she would be charged with violating the principle of filial piety. Even if the child did not agree, he or she has to take into account the opinions of relatives, neighbors, and colleagues who may consider such an action a violation of this principle. Gossip is a fearful thing.

Most Chinese doctors and nurses were trained in modern Western medicine (in contrast to those who practice traditional medicine); they have incorporated some Hippocratic principles into their Confucian background. The former's principle of "Do no harm" and the latter's principle of "Ren" (humaneness, loving-people, or beneficence) are fused.

Moreover, their personal experience during the Cultural Revolution made them extremely cautious about this kind of case; some physicians were condemned as murderers solely because they failed to save the lives of patients suffering from fatal diseases. No legal considerations have influenced

decision making so far, because courts and lawyers have been prohibited by the government from becoming involved in such cases since the 1950s on the grounds that legal professionals do not have adequate medical knowledge to give judgment. This situation is beginning to change, however, and courts are starting to consider such issues once more.

The salary of medical professionals is fixed and independent of how many patients they treat. And they do not concern themselves with the shortage of medical resources as much as the hospital managers or health policy decision makers. However, economic factors greatly influence the family's decision. If the patient were employed by the government or the military, or worked for a university or state-owned enterprise and thus enjoyed public health services (free medical care) and had a fixed salary, the family would tend to reject the patient's refusal of treatment. The families of patients employed in private or nonstate collective enterprises who are not eligible for public health care are likely to accept the patient's suggestion.

An irreversibly comatose patient who worked in a factory where I did manual labor during the Cultural Revolution has been given all-out life-saving measures in the hospital at the insistence of his children. The hospital proposed withdrawing treatment after several months, but the children rejected the idea.

In my opinion the way out of the dilemma raised in a case like Mrs. Randall's requires a conceptual shift. Medicine should be further humanized, and man's life made more humane. If a terminally ill patient refuses treatment in order to die humanely and with dignity, nobody, including his or her children or physicians, has the right to reject the patient's wishes. Instead they ought to respect the decision. An ethics committee should review the decision to ascertain if the patient is in a terminal condition and if it is his or her real wish.

Mrs. Randall is a competent patient. She understands the procedure being proposed and the consequences of refusal. She prefers a humane death to an inhumane life. Neither her children nor physicians have the right to deprive her of that final decision.

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When the Doctor Gives a Deadly Dose

At age seventy, Mrs. R. had become severely disabled by cardiac failure due to a damaged mitral valve. With her full and appropriate consent, she underwent a risky valve replacement, which initially went fairly well. However, within twelve hours after surgery, her cardiac output was clearly inadequate. Despite intensive care in the ICU, an adequate blood flow could not be sustained and an experimental cardiac assist device was implanted in her chest.

No right of the carpenter would be violated by this refusal. In my experience on an IRB, I have encountered cases in which cancer patients have demanded access to experimental protocols and cases in which families of Alzheimer's patients have demanded enrollment of senile relatives in experimental regimens. In all these instances, IRBs have properly maintained that no one has a right to be an experimental subject.

Nevertheless, assuming that the research has scientific merit and that the nerve used as a control can only be obtained from a living subject, I think that the experiment should proceed.

In cost-benefit analyses of research protocols, the IRB should weigh expected costs against expected benefits, where an "expected cost" is the probability of a loss multiplied by its severity. No special moral weight should be given to a loss the probability of which happens to be 100 percent. (Likewise no loss should be dismissed as negligible merely because its probability is low.) There is a common psychological tendency to prefer a greater expected loss of low probability to a lesser expected loss of very high probability. This tendency is irrational and should be resisted in the formation of policy.

Far from impugning the validity of the carpenter's consent, I would give it relatively high weight. Many prospective experimental subjects, reading the list of possible side effects, reason that since the side effects have low probability, they will not occur. On this assumption they volunteer for the experiment. This amounts to rating the expected disvalue of their improbable side effects as zero, a certifiable mistake in moral mathematics. (Across thousands of experiments, some subjects who say "it won't happen to me" must be mistaken.) The carpenter cannot be making this mistake, since he knows for sure what is in the bargain. His consent to mutilation is at least as informed and rational as the consent subjects commonly give to experiments that have improbable but catastrophic side effects.

There is a tendency among researchers and many IRB members to regard people with medical problems as morally ideal subjects for research on those problems, even when the prospect that the research will produce therapy for these subjects is nil. ("They have an investment in the disease," I have heard it said.) On the other hand, the participation of normal subjects, who have no investment in the disease, is viewed as altruism verging on the irrational. There is relatively little resistance to using severely ill Alzheimer's patients as subjects in Alzheimer's research, despite the logical tangles of proxy consent.

But the carpenter's sacrifice will be seen as abnormal and will be referred to journals as a problem in medical ethics.

I think that philosophers should be the last to assume that all action not directly linked to self-interest must be dismissed as irrational. The carpenter's desire to find some way to share his wife's fate is rooted in feelings, but these feelings are at the center of human life. For the bureaucracy to block this attempt on moral grounds would be a most inhumane application of humanistic ethics.

! - ignores the strong researcher bias to rationalize inferior of research

Nazi Data: Dissociation from Evil

Dr. A. is a researcher currently studying hypothermia. Most of his data come from experiments with fully informed volunteers whose responses are carefully monitored as their body temperature is lowered in a cold water tank or shiver chamber. Dr. A., of course, also relies on results gathered by previous hypothermia investigators.

Among this material, however, are certain data that trouble him. These are the observations of Nazi researchers at Dachau, who casually sacrificed an unknown number of lives in hypothermia experiments. After careful review, Dr. A. believes the Nazi data are reliable. Dr. A. considers this data to be particularly important, since he is both unwilling and unable to take his research subjects as far as the Nazis took theirs; at the same time, he is appalled at the prospect that a published report of his own investigations should be linked to crimes against humanity.

Dr. A. examines several options. He could simply reconcile himself to using the Nazi data; or reject the data on moral grounds and only cite other legitimate research; or use the data but cite it only with an explicit condemnation of Nazi methods and some account of his own ethical reservations concerning its use. Dr. A. is uncertain, however, if this last option would be a sensitive gesture or would merely add an element of hypocrisy to his use of the material.

How should the Nazi data be regarded? Is the data tainted by Nazi crimes or is it morally neutral information? Should researchers treat this information any differently than data gathered in more conventional ways?

Note: none mentions Kelly argument - (provoke future harm)

COMMENTARY

Mark Sheldon and William P. Whitely

use data if beneficial and...

The Nazi data challenge Dr. A. to turn inward and focus on his role and responsibility as a medical researcher.

In the interest of possible future good, perhaps even saving lives, is it acceptable to make use of data collected through mutilation, torture, and death? Is it better not to use the material at all? Is this a sacrifice a moral civilization must make in the memory of those who were lost to the silence of history? The fundamental obligation of medicine is to protect and preserve life. Thus, if Dr. A. believes that use of the data will contribute to the preservation of human life, he should cite it in his own research.

As a researcher, Dr. A. is motivated by a desire to contribute to scientific understanding and to improving and preserving life. Nevertheless, he realizes that the data are not morally neutral. Nazi medicine lost sight of

its duty to preserve life. Dr. A. is aware of the barbarity that produced the data and he must wonder if the men, women, and children who were tortured and murdered will be further violated by use and citation of the data. This question is difficult because it is impossible to know what the victims themselves would have wanted done with the data. It is also impossible to discern what effect using the data will have on society, on the collective memory of the Holocaust, or on the future of medical research. Because of these uncertainties, Dr. A. must acknowledge that by using the data, he may contribute to the desecration of the victims and their memory.

** orthodoxy, utilitarian analysis*
 Kristine Moe maintains that use of data from Nazi research is justifiable under certain conditions. The data must be reliable, unavailable from any other source, capable of contributing to the greater good, and publication must be accompanied by a clear condemnation of the means by which the data were collected ("Should the Nazi Research Data Be Gited?" *Hastings Center Report*, December 1984). Moe's conditions give Dr. A. some guidance on what he should do. The first two conditions are clear. They are scientific issues stipulating that Dr. A. should not use the data if it is unreliable or if similar information is available from ethical studies. Dr. A. appears to have resolved these questions responsibly.

is possible, other work, remarks, dispute, arrangement, by, no more
 The third condition is confusing. It suggests that Dr. A. should try to calculate both the harmful and beneficial effects of using the data and arrive at an estimate of the "greater good." It is not clear how Dr. A. would conduct these calculations or whether anyone would agree with his conclusion. The "greater good" is an abstract notion and it is difficult to know when it has been adequately met.

The central issue and the concern that originally called Dr. A. to this profession, however, is the desire to contribute to humane understanding to preserve life. If the data can preserve life, Dr. A. not only can, but should use it.

The fourth condition requires a clear condemnation of the means by which the original data on hypothermia were collected. This condition is also difficult because it is not obvious how the condemnation should be accomplished. What specific characterization should be given to the Nazi experiments? "Inhuman" is an understatement that does not reflect adequate condemnation. "Bestial" and "vile" would be more satisfactory. Or should Dr. A. focus on the victims rather than the perpetrators? Should he describe the terrible suffering of the victims so that the reader understands the human cost of the data? If the data are a regular and important part of his work, should he try to educate his colleagues and the public by speaking and writing about the medical crimes?

By using the data, Dr. A. may be desecrating the memory of the victims. Thus he is faced with a profound challenge creatively and continuously to sustain a sense of condemnation that keeps alive the memories of the victims and fights against a future that replicates the past.

COMMENTARY

Brian Folker and Arthur W. Hafner

In some ways, the issue faced by Dr. A. is one of meaning. The Nazi data are unique in that they are imbued with meanings seldom encountered in the realm of rational, scientific enquiry. This dimension of the data has gone virtually unacknowledged in current debates over their proper status. Most who oppose use of the data identify condemnation of the Nazi researchers as their principal objective. It seems reasonable, however, that consideration of the meaning of the data in a contemporary context should be an equally important factor for those faced with a choice such as Dr. A.'s. Researchers need to fully understand what their use of the data implies, and this requires an answer to two separate but related questions: What meanings are inherent in the Nazi data? What would be the full value of any gesture one might choose to make regarding these data?

Perhaps the most intriguing question on which the issue of proper use turns is whether or not scientific data can acquire a moral taint. Common sense seems to indicate that a parcel of information about the physical world is morally neutral. Since our society so highly esteems an understanding of the physical universe, some might even argue that any such information is inherently valuable. Why should this be any different for some apparently reliable data (for instance, what researchers at Dachau learned about the resistance of the human body to cold) simply because the circumstances under which they were gathered horrify us?

However, regarding the data as morally neutral ignores an important aspect of human discourse. Disseminated through contemporary journals, such data become tokens in the daily exchange of ideas and information between scientists. Any communicative token—be they words, symbols, or a set of research data—achieve a good part of their meaning through association. A cross is only the transection of two pieces of wood, unless one happens to be a Christian; a swastika is a similar figure, unless one happens to identify with the National Socialists—or their victims. It is of course correct to observe that, unlike a cross or swastika, the data in question have a concrete, primary meaning that is not necessarily associated with crimes against humanity. In the practical world of exchanged meanings, however, the historical associations are both undeniable and overwhelming.

Is it possible for scientists to ignore these meanings or at least place them in brackets and set them aside? It would be easier to say yes if the world of scientific discourse were closed. Many researchers are motivated by a powerful desire to discover truth or save lives. They may, after careful consideration, decide that the demands of their calling outweigh the data's associative meanings, no matter how horrific. Such researchers must first consider, however, the exchange that transpired between science and the public. We are unavoidably identified with the words, ideas, and symbols in which we trade, and responsible for all the meanings they convey. Researchers must be con-

* cerned with the perception that they are sometimes insensitive to the ethical dimensions of their work. If a scientist cavalierly gives inhumanely extorted data a place in that work, public confidence is rightfully shaken.

Our ability to punish Nazi scientists by refusing to cite their data has vanished after the lapse of almost half a century. Nevertheless, this outwardly directed meaning represents only a portion of the total significance such a gesture may contain. Such expressions serve also to make important statements about the people who perform them. Indeed, it is the self-defining nature of our use of the Nazi data that is most important.

Dr. A. (should reject) the Nazi data. We would not wish our names, our work, or our laboratory to be associated with such heinous meanings. This course of action grows out of convictions that contemporary scientific inquiry can and should proceed in a thoughtful, morally reflective atmosphere. However, each researcher must make such a decision for him- or herself, cognizant of the fact that the moral meaning of the data is an inescapable presence that must be weighed against a legitimate need for the information. Whatever decision a researcher arrives at should not stem primarily from a desire to condemn the Nazis or even to commemorate their victims but rather out of a concern for himself as a moral being.

COMMENTARY

Willard Gaylin

we must not become "onlookers" (& accomplices)

Despite the oft-repeated Luddite statement that in science "anything that can be done, will be done," much that could be done in human research and that would have been beneficial to do, was not done because it was inhumane. We do not separate twins at birth to study the influences of heredity and culture on identical genetic creatures. We do not inflict injuries on volunteers to test therapeutic procedures. We do not allow people to "volunteer" for radiation experiments or burning mutilation—even though the data accumulated could be of enormous help in saving lives; more people suffer from severe burns than from freezing in cold water. We do not, to be specific, replicate the Nazi experiments. On a utilitarian calculus it might be worth it. "We" do not do it. The Nazis did.

The Holocaust is beyond comprehension. The destruction of six million Jews for no other reason than that they were Jews would have been sufficient to mark this as a monstrosity of the first order. The torture and pain, humiliation and degradation visited upon them adds its dimension of surrealistic bewilderment. That this was done not by barbarians in some precivilized time, but by what had once been considered the most civilized country in Europe—by the descendents of Goethe and Kant, the *Landsleute* of Beethoven and Bach—drives us into a blind alley of disorientation. That it was done with the scientific elegance and obsessive meticulousness characteristic of German technology is an absurd and painful paradox.

To examine the detailed activities of the camps is to risk being turned to stone. But even when one protects oneself from the Medusa's head, and ex-

amines it only through reflected images of the *Zuschauenden*—the onlookers—our sensibilities are assaulted by disbelief and despair. Explain the silence of the German and Austrian people who knew and in their silence collaborated; the uncharitable indifference of those Christian institutions of charity, the Protestant and Roman Catholic churches; the absence of humane grace on the part of our most humanistic leaders of the western world, Winston Churchill and Franklin Delano Roosevelt. The indifference of the world at large is what makes of the event an unfathomable morass.

After forty years of attempting to "understand" the Holocaust I have reluctantly admitted defeat. If one cannot understand then what can one do? One can remember. One can make sure that others remember. And one can refuse to be added to the list of onlookers, which brings us to the current case. There is an easy technical way out. "Dr. A. believes the Nazi data are reliable." Why should one believe anything from the Nazis is reliable? But it is not necessary to find technical reasons for avoiding the substantive problem. There is no ambiguity here. Let us accept the ingenuous faith of the researcher. We cannot cite these atrocities. To use this data is to become an onlooker, and beyond that, an accomplice. To publish this data in a scientific journal is to legitimize it. *in the past & also implied in the future - bad*

We cannot remain silent while others rationalize the use of such data. By remaining silent we join all those other silent onlookers. The great poet of the Holocaust, Nellie Sachs, fixed their guilt:*

You onlookers

Whose eyes watched the killing

As one feels a stare at one's back

You feel on your bodies

The glances of the dead.

...
You onlookers,

You who raised no hand in murder

But who did not shake the dust

From your longing

You who halted there, where dust is changed

To light

... does "good science" demand "good scientists"? - science is a human function, & if conducted inhumanly can't itself be humane and

To use this "data" is to give it, beyond credence, honor. The Nazi medical experiments were but threads in the tapestry of evil that was the Holocaust, but no thread must be dignified by its utility. We must not add our numbers to the multitudes of onlookers who slept peacefully through the nights of anguished cries while dreaming their sweet dreams of a better tomorrow. *confuse utilitarian*

*Nellie Sachs, "You Onlookers." In *O the Chimneys* (New York: Farrar Strauss, 1967), p. 19. Poem trans. by Ruth & Matthew Mead.

The Heart of the Matter

A heart transplantation team at a major urban teaching hospital invariably has more candidates for heart transplantation than hearts available to transplant. The program is known to benefit both low-risk and high-risk patients. Nevertheless, 30 percent of the candidates die before a heart becomes available. Members of the transplant team, who are both medical practitioners and scientific researchers, consider alternative sources of organs and decide upon the hearts of chimpanzees.

The researchers realize that they are entering upon relatively uncharted waters, despite the close evolutionary link between human beings and chimpanzees. However, they have previously performed a series of preparatory experiments transplanting hearts between cynomolgus monkeys and baboons. Though all the hearts were ultimately rejected due to the incompatibility of the two species' tissue types, there was temporary survival—an average of eleven weeks—sufficient to “buy time” for potential transplant recipients.

If the analogy between monkey/baboon and chimpanzee/human being holds, the chimpanzee heart could serve as a temporary “bridge” to a human heart if and when one becomes available. For various reasons, medical and otherwise, the transplant team considers the chimpanzee heart preferable, as a bridge, to an artificial, mechanical heart. Moreover, it is possible that the chimpanzee heart could become a permanent replacement, if problems of immunological rejection could be overcome. Still further, this experiment might lead to scientific knowledge allowing the use of other types of animal hearts, for example, those of pigs or cows. This would solve—practically, if not ethically—the chronic problem of the insufficient supply of transplantable hearts.

Confounding this possible human benefit and heady medical technology are certain inexorable facts. Chimpanzees are an endangered species. There are about 100,000 chimpanzees left in the world and about 2,500 in captivity in the United States. International trade in chimpanzees is banned, breeding in captivity is difficult, and capture of wild chimpanzees is “inefficient” in terms of preserving individual lives. For every wild chimpanzee captured and delivered to its destination, as many as ten other chimpanzees die.

Moreover, captive chimpanzees are much in demand for other forms of scientific and medical research. Finally, the scientific merits of using chimpanzees in research and particularly in this medical therapy carry a correlative ethical albatross. Can we, for such a purpose, ethically justify the use of such a complex and elaborate form of animal life, in several behavioral activities so close to our human selves?

Should the transplantation team go ahead with its experiment? Should the project be approved by the institution's Institutional Review Board (IRB) and Institutional Animal Care and Use Committee (IACUC)?

COMMENTARY

Strachan Donnelley

If the transplant team is embarking upon uncharted waters, the ethicists are in the same boat. There seem to be no adequate or widely accepted ethical principles with which to decide this case. We should perhaps immediately ascribe to Socratic wisdom and state frankly that we know that we do not know. Yet I think we can make some headway and point to the problems that we need to resolve.

There are numerous ethical issues surrounding this xenograft—the transspecies transplant of a chimpanzee heart into a human being. The IRB must struggle with the problem of what would constitute adequate informed consent for this unprecedented “innovative therapy” or experiment. Both the IRB and the IACUC must satisfy themselves that the medical professionals/researchers are fulfilling the ethics of good science—that the preparatory experiments were sound and that there is a reasonable expectation of good results—both for the human research subjects/patients and for the advancement of significant scientific knowledge. However, the latter question is intricately tied up with perhaps the most difficult and interesting ethical issue—this particular use of chimpanzees in scientific research and medicine.

A singular virtue of this case in animal ethics is that it bypasses the usual ethical concern with animal pain and suffering and focuses directly on the issue of the ethically legitimate and illegitimate uses of animals for human purposes. This issue hinges crucially on the relative moral status of human beings and the various species of animal life. If one tends toward extreme positions, there is no ethical dilemma. If animals have no moral status and are not objects of moral concern, we can freely use them for our own purposes (e.g., as supplying hearts as “bridges” to human hearts). If we accord chimpanzees a moral status near, if not equal, to our own, we should prohibit their use in most, if not all, painful or ethically harmful research and certainly in this particular experiment.

However, if we tend to neither extreme, but consider chimpanzees as important objects of concern, though of less ethical significance than human beings, then things become decidedly less simple. We are confronted with ultimate questions about our status in the overall scheme of the world and about our proper relation to nature and the realm of animal life. Concerning all this, there is no philosophic or ethical consensus, though I would argue for a fundamental ecological perspective and a conception of man as within nature.

From such a perspective, animal individuals and communities of individuals are understood to be essentially interconnected. Individual animal lives are lived out on various species-specific levels of activity, some more complex, elaborate, and, thus, ethically significant than others. Organic, worldly “activity” is taken to be the “ultimate good,” and thus the fundamental focus of ethical concern. Our final ethical duty is therefore the protection of the

ongoing realm of life as a whole, with its various interlocked levels of animate being. Our penultimate ethical duty is concern for finite and mortal individual lives (the concrete instances of life), relative to their unequal status of ethical significance.

According to this philosophically speculative and tentative position, it would be unethical to use chimpanzees for merely therapeutic purposes—that is, to use individual chimpanzees for the sake of individual human beings. Given the open-ended demand for “bridge hearts,” this already endangered species of richly significant life would soon be extinct. Human life would remain finite, mortal, and vulnerable to all the vicissitudes of worldly, metabolic existence, while the particular and complex goodness of chimpanzee being would have vanished from the world. The ethical costs of such human self-concern, both for human beings and for the animal kingdom as a whole, seem unjustifiable. *even on utilitarian grounds, long-term benefits*

However, if this procedure were deemed a potentially significant scientific experiment that in no way threatened the presence of “chimpanzee being” in animate nature, then it might be ethically justifiable. If there was the real potentiality of the use of animal hearts of nonendangered species (e.g., pigs or cows), if we deemed this an ethically appropriate use of individual animal lives, and if the chimpanzee experiments were crucial to the possible realization of this novel therapy, we could ethically justify the use of a limited number of chimpanzees—if this were an adequate allocation of a very scarce animal research resource and if we satisfied the ethical demands of experimentation on human research subjects.

These are all very big “ifs.” Ethical caution should here carry the first word, in the face of parochial human self-interests and medical technological hubris. However, a possible ethical justification could be based on the intrinsic goodness of organic, worldly activity and the varying ethical significance of different levels of animate being. This, of course, would be to subscribe to a substantive speculative vision of the world. Yet this seems the fate of all ethical positions—that they are ultimately based in some particular metaphysics.

COMMENTARY

Willard Gaylin

Following the wisdom of the Queen of Hearts (“Sentence first—verdict afterwards”) I will start with my conclusions. Although trees may have standing, animals have no “rights.” In the world of morality—as in the world of politics—the animate (and the inanimate) exist, are valued, respected, esteemed, judged, considered, dealt with or destroyed, all in service of the purposes and interests of humankind.

This position has in the past been attacked as being unfairly anthropocentric. I acknowledge my bias, although I would point out to critics that the position was most firmly established in the religious tradition of the Old

Testament and confirmed in that same tradition by such modern philosophers as Kant. With the inherent self-confidence of his Lutheran morality, Kant said, “The first time he [man] ever said to the sheep, ‘Nature has given you the skin you wear for my use, not for yours,’ ... he became aware of the way in which his nature privileged and raised him above all animals.” We stand above the general animal host.

I oppose the attribution of rights to animals because I fear it diminishes the special status of *Homo sapiens*. The respect for human beings demands a dignity granted our species beyond any qualitative comparison with others. We are *sui generis*. We also pay a price. This unique nature imposes a special moral obligation on our species, which is why only we human beings are able, and willing, to agonize about other species.

There is no way to defend or argue the special dignity of humankind within the brief context of a case history. But even within the severity of my position the case of the chimpanzee hearts raises moral dilemmas. It is directly within the purposes of humankind to treat animals with compassion, empathy, sensitivity, and understanding; to have reverence for those common qualities we share with the higher primates; and to be aware that with the mutability of our nature the way we honor and revere other creatures and other things will define the degree to which we have been true to our humanity. If human nature is so perverted as to be indifferent to suffering and blind to beauty, what is left of that nature is no longer “human”—therefore not worthy of its special role in the moral universe.

This does not mean that living things may not command respect. But all animals are not created equal. This is recognized implicitly in the Animal Welfare Act. In this act “animal” is defined as “warm-blooded animal.” As Sara Swenson has noted, the word “animal” itself is here defined in anthropocentric terms of the animal’s usefulness/relationship to human beings, rather than by criteria such as intelligence or biological complexity.

Some animals have less value than inanimate structure; some animals have negative value. I do not grieve for the destruction of *T. pallidum*, that beautiful and delicate spiral organism that is the cause of human syphilis. To destroy this entire species would be a blessing, whereas if someone were to blow up the Grand Tetons or willfully destroy Botticelli’s “Primavera,” a greater moral crime would have been committed through the destruction of these inanimate “things.”

Nonetheless, this case is a difficult one. Heart transplantation is not necessarily my highest priority of research in this period of limited resources. But in this specific case it deals with the survival of children which, indeed, is high on my priorities. However, it places at risk that creature most nearly human, and therefore most worthy of respect, the chimpanzee.

To debate the principles, beyond the case history, let us now not concern ourselves with the value of heart transplants, or other specifics of the current state of scientific knowledge. Let us assume a valuable and available technology, and go straight to the heart of the moral dilemma.

Chimpanzees have enormous charm, sensitivity, great intelligence and a strong kinship with humanity. Should this be sacrificed for human ends—and with what limits? The implicit issue evolves into the following dilemmas: Given a promising or proven procedure would you sacrifice a chimpanzee for a trivial human need? I suspect most of us would not. Would you sacrifice a chimpanzee for a child's life? I suspect most of us would. Would you sacrifice the entire species of chimpanzees for the entire species of Homo sapiens? I suspect most of us would. And now finally the hard question. Would you risk sacrificing the species of chimpanzees to relieve the pain and suffering and premature death of many children? Here, I, at least, emphatically would. Others would not. *Kantian? same one could even risk of*

Our current understanding of anthropology is replete with the suggestion of humanoid species—higher than the chimpanzees—which have died out for unknown causes of climate or competition. Such is the “cruelty” or actually the moral indifference of nature. It is only with the introduction of human sensibility, human empathy, and human contacts for identification that we—alone among creatures—consider the “rights” of other species. It is the nobility of the human being that some of our misguided members might sacrifice their own children for the preservation of a kindred, living creature. I am pleased for the presence of such advocates (they honor our species) even while I reject their sentimentalities. I am, however—even with my coarser sensibilities as expressed by my willingness to sacrifice the chimpanzee—still, I hope, within the limits of decency that define that glorious discontinuity—Homo sapiens. *chimp species + possible future use of them*

Selected Biography

Part Four: Research with Living Subjects

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intrinsic value (only human - or also animal)
v.
utility (short + long-term)