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Do Physicians Have an Ethical Obligation to Care for Patients with AIDS?

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DO PHYSICIANS HAVE AN ETHICAL OBLIGATION TO CARE
FOR PATIENTS WITH AIDS?

A Thesis Submitted to the Yale University
School of Medicine in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Medicine

by

Nancy Rockmore Angoff

1990

ABSTRACT

DO PHYSICIANS HAVE AN ETHICAL OBLIGATION TO CARE FOR PATIENTS WITH AIDS?

Nancy Rockmore Angoff

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This thesis responds to the question: Do physicians have an ethical obligation to care for patients with Acquired Immunodeficiency Syndrome (AIDS)? First, the social and political milieu in which this question arises is sampled. Here we find physicians as well as other members of the community exclaiming an unwillingness to be exposed to people with AIDS. Next, laws, regulations, ethical codes and principles and the history of the practice of medicine are examined, and the literature as it pertains to these areas is reviewed. The obligation to care for patients with AIDS, however, cannot be located in an orientation to morality defined in rules and codes and an appeal to legalistic fairness.

By turning to the orientation to morality that emerges naturally from connection and is defined in caring, we find that physicians do, indeed, have an ethical obligation to care for patients with AIDS. Through an exploration of the writings of modern medical ethicists, it is clear that the purpose of the practice of medicine is healing which can only be accomplished in relationship with the patient. It is in relationship to patients that the physician has the opportunity for self-realization. In fact, the physician is physician in relationship to patients and only to the extent that he or she acts virtuously by being morally responsible for and to those patients. To not do so diminishes the physician's ethical ideal, a vision of the physician as good physician, which has consequences for the physician's capacity to care and for the practice of medicine.

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I thank those of my teachers who have shown me that they find strength and gratification in the physician-patient relationship.

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TABLE OF CONTENTS

Chapter 1: Introduction.....	1
Chapter 2: AIDS: The Milieu.....	5
Chapter 3: A Search for the Obligation in Tradition.....	21
Chapter 4: Modern Ethical Models of Medical Care.....	55
Chapter 5: The Practice of Medicine.....	71
Chapter 6: The "Core" Practice of Medicine.....	85
Chapter 7: The Essence of the Practice of Medicine.....	93
Chapter 8: Conclusion.....	126
Bibliography.....	130

Chapter 1: Introduction

Little did anyone know in 1981 when reports of the first cases of Acquired Immunodeficiency Syndrome (AIDS) began to trickle in that the decade would come to represent a time of major conflict and challenge for the practice of medicine. That challenge would encompass the realm of science and technology in its most intimate interface with humanity. There is no doubt that many physicians met the challenge with strength and dignity and courage. However, there was also turmoil, confusion and fear that resulted in some physicians declaring what to many was unthinkable, that they would not care for patients with the disease known as AIDS. There followed an intense debate in the media and in the medical literature as well as in the halls of hospitals and medical schools across the country that centered on the following question: Do physicians have an ethical obligation to care for patients with AIDS?

No one seems to recall similar questions having been open to such intense query: Do physicians have an ethical obligation to care for patients with tuberculosis? Do physicians have an ethical obligation to care for patients with polio? An explanation commonly offered is that before antimicrobials physicians knowingly became physicians in the face of personal risk, and after antimicrobials physicians complacently grew to expect negligible personal risk. AIDS, however, "...ruptured

this psychological aura of invulnerability."¹ Of course, it is more complex. AIDS presents us not only with fear of a potentially deadly virus, but of one with strong emotional connotations built around the vehicles of transmission of the virus, blood and semen; the mode of transmission of the virus, piercing needles and sexual intercourse; and the kinds of people we think are more apt to transmit it, homosexuals and intravenous drug abusers.

Other explanations for physicians' reluctance at this time have been offered as well. Loewy states, "No longer is the society in which the physician functions and in which are his/her roots the 'tight little island' of yesteryear. In many respects it is more egocentric, more hedonistic, more pampered and spoiled, less community oriented and more dedicated to the self.... Our media and our propaganda extol 'rugged individualism' and often demean social action."²

As a medical student I find myself caught in the middle of this debate that affects me as the physician I am becoming. Each medical student and beginning physician must come to terms with strong feelings about this disease and about caring for patients with this disease. As one physician put it, "At some point in our professional lives each of us works out a personal bargain

¹Nolan, Kathleen, and Bayer, Ronald, "AIDS: The Responsibilities of Health Professionals," Hastings Center Report, April/May 1988, 18:1.

²Loewy, Erich H, "Duties, Fears and Physicians," Social Science Medicine, 1986, 22:1363-1366. p. 1366.

with society. My own bargain renders the evil, pain, and inconvenience of caring for patients with AIDS as much a part of my job as the care of any other critically ill patient. Many of my colleagues have bargains that state just the reverse."³

To me and to many people with whom I speak, it feels wrong to refuse to care for any sick patients, but when asked we have been unable to substantially defend our position. Nor have the literature or the experts offered much help. At a seminar on "AIDS and Professional Responsibilities" in October 1987, at the Hastings Center, experts in the fields of law, medicine and ethics concluded that a search of the armamentaria of their fields revealed no clear obligation to treat. Where then do feelings fit in an ethical debate? If one "feels" that caring for patients with AIDS is morally right and that refusing to care is morally wrong, can an ethical foundation be found to support those feelings?

In this thesis I shall respond to the question, do Physicians have an ethical obligation to care for patients with AIDS? I shall look at the practice of medicine as a great unfinished tapestry woven over the years to tell a story, added to by the individual physicians whose own stories are woven into the larger tapestry, enriched with threads of commitment, care and relationship and dulled with threads of self-interest. I shall begin by looking at the social and political milieu in

³Zuger, Abigail, "AIDS on the Wards: A Residency in Medical Ethics," Hastings Center Report, June 1987, 17:16-20. p. 19.

which this question first arises. I shall then examine laws, regulations, ethical codes and principles, and the history of the practice of medicine as they pertain to this question. These will be followed by an examination of several modern models of medical ethics. Finally, I shall turn to a different orientation to morality for an answer to this question.

Chapter 2: AIDS: The Milieu

I've thought about what I'll do when the time comes and I'm so sick that I need someone to take care of me. I don't know what I'll do. I might not live to see that. That goes through my mind all the time. Nobody's gonna take care of you for nothing.

A person that's going through it needs someone who's going through it. Otherwise you can't understand. It's like my Black-American History teacher who was white and said, "I understand. I understand." Well, you don't understand because you don't understand unless you're going through it yourself. There's no cure for it. It's different from just being sick and going home next week and living your life. This is totally different.⁴

Physicians Refusing to Care

When the first physicians proclaimed their refusal to care for patients with AIDS, the public and the profession were left to question what it means for physicians to refuse to do what they have been educated and trained to do. Physicians are, after all, members of the community, and in refusing to care for patients with AIDS,⁵ they are both echoing the voices of turmoil,

⁴Excerpts from stories told to me by patients with AIDS will appear in italics at the beginning of some of the chapters. These excerpts have been extracted from discussions I had with patients hospitalized during the spring of 1989.

⁵For the purpose of this discussion, unless otherwise specified, the use of the term AIDS will also refer to being positive for Human Immunodeficiency Virus (HIV). While the degree of one's infectivity may well change during the period of infectivity, it is the obligation to treat those perceived as capable of infecting others that is being examined here. (On the question of varying virus burden see, for example, Ho, David et al, "Quantitation of Human Immunodeficiency Virus Type I in the Blood of Infected Persons," and Coombs, Robert W. et al, "Plasma Viremia in Human Immunodeficiency Virus Infection," both in The New England Journal of Medicine, December 14, 1989, 321:1621-1631.) The report issued by the Presidential Commission on the Human Immunodeficiency Virus Epidemic stresses that HIV infection more adequately takes into account the full course of the disease

confusion and fear of that community and adding to them.

On July 11, 1987, an article on the front page of The New York Times stated that Dr. Terence M. Schmahl, chief of the department of thoracic and cardiovascular surgery at St. Luke's Hospital in Milwaukee, was "...one of a very small but visible number of medical practitioners around the country who are refusing to care for carriers of the AIDS virus."⁶ The article quoted Dr. Schmahl as saying, "'I've got to be selfish.... I've got to think about myself; I've got to think about my family. That responsibility is greater than to the patient.'"⁷ Dr. Schmahl's stand was attributed to two factors; one was fear of contracting an incurable contagious disease and the other was discrimination against male homosexuals who made up the largest single group of people at risk of contagion.

The public stand taken by Dr. Schmahl was also taken by Dr. Bruce Wilbur, a private cardiovascular surgeon in Mountainview,

rather than focusing on the later stages of the disease. (See Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic, Washington D.C.: Presidential Commission on the Human Immunodeficiency Virus Epidemic, 1988.) Indeed, most of the medical community is making the effort to differentiate between the various stages of the disease in individuals by referring to asymptomatic infection, AIDS or AIDS-related complex. AIDS, however, is the term currently understood by the medical and general community to capture the symbolic and metaphoric aspects of the disease as discussed by Sontag. (See Sontag, Susan, AIDS and Its Metaphors, New York: Farrar, Straus and Giroux, 1989, and Illness as Metaphor, New York: Vintage Books, 1979.)

⁶Gruson, Lindsey, "AIDS Fear Spawns Ethics Debate As Some Doctors Withhold Care," The New York Times, July 11, 1987, p. A1.

⁷Gruson, p. 12.

California, who stated, "'They [health care workers] don't like having to work on people with a fatal and possibly communicable disease.... I know I don't.... I did my time. I had a nine-year residency and took care of everything bad you could imagine. I put myself at risk, I had hepatitis. I don't want to be forced to do it anymore.'"⁸

At a meeting of the American Hospital Association in July, 1987, there was a panel discussion devoted to the topic of developing guidelines for dealing with physicians who refuse to treat patients with AIDS. Dr. Gregory L. Henry, an emergency room physician practicing in Michigan, announced, "'I will no longer perform mouth-to-mouth resuscitation.... I consider that an unfair risk to myself and my family.'"⁹

Prager states, "Although the number of doctors who have publicly announced their boycott of AIDS patients is small, almost certainly there is a much larger number who sympathize with their more vocal colleagues and will follow in their footsteps."¹⁰ Along with these well-publicized declarations of three established physicians there have been reports of other examples of physicians' attitudes as they relate to caring for patients with AIDS. In a study of 157 post-residency physicians

⁸ "Physicians, Nurses Cope with Concerns about Infection," American Medical News, October 2, 1987, p. 28.

⁹ "Refusal to Treat AIDS Addressed," The New York Times, July 29, 1987. p. A1.

¹⁰ Prager, Kenneth M, "What? Physicians Won't Treat AIDS?" The New York Times, October 23, 1987.

in three large cities with moderate but increasing AIDS prevalence, Kelly et al compared physicians' attitudes toward caring for patients with AIDS versus physicians' attitudes toward caring for patients with leukemia. They found that, "...physicians considered the AIDS patient to be more responsible for his illness, more deserving of what has happened to him, to be experiencing more pain but less deserving of sympathy and understanding, more dangerous to others, and more deserving of quarantine."¹¹ Kelly et al conclude, "Attitudes of this kind indicate that many physicians experience discomfort interacting with AIDS patients which can interfere with the development of a positive, constructive, and open doctor/AIDS patient relationship."¹²

Link et al studied medical and pediatric interns and residents in four New York City house staff training programs. They found that, "...25 per cent of all house officers surveyed would not continue to care for AIDS patients if given a choice.... Furthermore, 36 per cent of medical and 19 per cent of pediatric residents believed their AIDS experience made them less likely to care for AIDS patients in their future."¹³ Most

¹¹Kelly, Jeffrey A. et al, "Stigmatization of AIDS Patients by Physicians," American Journal of Public Health, July 1987, 77:789-791. p. 790.

¹²Kelly, et al, p. 791.

¹³Link, R. Nathan et al, "Concerns of Medical and Pediatric House Officers About Acquiring AIDS from Their Patients," American Journal of Public Health, April 1988, 78:455-459. p. 457.

interesting is the finding that "Twenty-four per cent of the house officers believed that refusing to care for AIDS patients was not unethical."¹⁴

Zuger interned in 1981 at New York City's Bellevue Hospital. She describes covert refusal of house staff to care for patients with AIDS: "The AIDS patient who never quite gets visited on morning rounds 'because there's nothing new to say,' 'because all the students upset him,' 'because the intern will come back and talk to him later' is all too familiar. So is the thin, feverish young man who waits somewhat longer than his turn in the emergency room."¹⁵ Kemena, a medical student, had an experience much like Zuger's when he was assigned to care for a young homosexual patient with AIDS. "Each morning our team made rounds on the ward, and we would always stop outside James' room. It was a rushed pause. My resident never entered the room, but the attending physician occasionally would look around the curtain."¹⁶

Fear of Infection

There are many reasons posited for physicians behaving this way two of which have already been mentioned, fear and discrimination. Drs. Schmahl and Wilbur and Henry cite fear of

¹⁴Link et al, p. 457.

¹⁵Zuger, p. 19.

¹⁶Kemena, Lloyd "Ben", "James," The New Physician, January-February 1986, 19-22. p. 20.

getting AIDS as their major motivation to refuse to care for these patients. Other physicians, as well, confess to worrying about the risks and uncertainties involved in contracting this virus. One study of 56 medical house officers at San Francisco General Hospital found that 91 per cent "...were at least 'mildly anxious' about caring for AIDS patients...."¹⁷ That study reports that it was not uncommon for house officers to experience unpleasant dreams or nightmares about AIDS. Furthermore, some physicians believe that what is known about HIV cannot be known with certainty. It has been reported that several Florida physicians have contended that, "No one, based on current medical evidence, can be sure of how HIV is transmitted...."¹⁸ In a letter to a journal editor, another physician declares, "Until time has shown that the risk is truly miniscule, or until an effective vaccine becomes available, I consider my personal fears about AIDS to be quite rational."¹⁹

What is known about the risk to health care workers of acquiring AIDS? Allen states, "Although isolated cases of HIV infection in health care personnel have created a high level of anxiety about the risk of treating such patients, the actual

¹⁷"MD: 'Very Normal' for health workers to Fear Caring for AIDS Patients," American Medical News, October 2, 1987. p. 27.

¹⁸"Arcadia Physicians Defend Their Position in AIDS/School Dispute," American Medical News, September 25, 1987, p. 3.

¹⁹Clark, John B. Jr., "The Physician's Ethical Obligation to Take Care of Patients in Times of Plague" [Letter], The Journal of the American Medical Association, March 4, 1988, 259:1325.

probability of contracting infection is extremely small."²⁰ The major route of infection in health care workers has been accidental needle stick. Three health care workers reportedly became infected after exposure to HIV-positive blood on their skin or mucous membranes. In each of two studies done by the Centers for Disease Control (CDC) of health care workers exposed to HIV, 0.44% and 0.54% respectively were found to be seropositive after exposure. In several other studies, none of those exposed were found to seroconvert. Allen places a maximum risk estimate at one seroconversion per 200 incidents of exposure.²¹ There remain some factors, however, which may affect this estimate about which little is known, for example, the size of the inoculum and co-factors involving the health status of the recipient. Therefore, there is a definite risk of exposure to infection by this deadly virus estimated to be "small" which can be reduced even further by careful adherence to protective guidelines. Some physicians feel, however, as with winning the lottery, it does not matter how small the odds are, all that matters is that it happens to me. For some physicians, no level of risk of exposure to a deadly disease is acceptable.

²⁰Allen, James R., "Health Care Workers and the Risk of HIV Transmission," Hastings Center Report, April/May 1988, 18:2-4. p. 2.

²¹Allen, p. 4.

Discrimination

The other motivation mentioned for refusal to care for patients with AIDS is discrimination. Kemena is wary of suggesting that his team spend more time with James "...lest my remarks be misinterpreted as enthusiasm for this homosexual patient."²² Add to discrimination against homosexuals, discrimination against drug addicts who, for the most part, are also members of minority groups.²³ "Drug addicts--the other large category of patients--are notoriously unpopular patients on hospital wards; young physicians seeking their own equilibrium on the wards are always ready to discourse on the 'manipulative and demanding addict personality,' the futility of treating their 'self-inflicted' diseases."²⁴

There are other reasons, as well, for physicians' reluctance to care for patients with AIDS including that the victims of this disease are often young, a fact found disturbing to the for-the-most-part-also-young house staff, and that they are beyond the pale of any known medical cure leading to a sense of impotence on the part of their care givers.²⁵ One health care worker states, "'It's not AIDS itself. That's not what people are reacting to. There are two main issues: sexuality and

²²Kemena, p. 20.

²³Schmidt, William E., "High AIDS Rate Spurring Efforts for Minorities," The New York Times, August 2, 1987. p. 1.

²⁴Zuger, p. 18.

²⁵Zuger, p. 17.

death."²⁶ In other words, in addition to fear of exposure to a deadly virus is the stigma attached to a disease that may be sexually transmitted. Brandt states,

First, venereal disease is considered a disease of behavior, a punishment (be it just or unjust) for those who take risks. Second, the danger of venereal disease is raised to argue (at least implicitly, but often explicitly) for a more restricted sexuality. And finally, venereal infection is viewed as not just a disease but as a symptom of a more profound sociosexual maladjustment, a failure of control.²⁷

Thus, victims of AIDS are considered to have transgressed in some unfortunate and disagreeable way. They are people with whom physicians do not wish to associate, with whom physicians do not wish to be associated and like whom physicians do not wish to consider themselves. In addition to the prospect of death, AIDS suggests other potentially horrible prospects. Sontag says, "In contrast to cancer, understood in a modern way as a disease incurred by (and revealing of) individuals, AIDS is understood in a premodern way, as a disease incurred by people both as individuals and as members of a 'risk group'--that neutral sounding, bureaucratic category which also revives the archaic idea of a tainted community that illness has judged."²⁸ In his column for The New York Times, Rosenthal writes about a physician

²⁶Wiebe, Christine, "Professional Demands, Human Frailties: Doctors Respond to AIDS," The New Physician, January-February 1986:14-36. p. 17.

²⁷Brandt, Allan M., No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880, New York: Oxford University Press, 1987. pp. 179-80.

²⁸Sontag, Susan, AIDS and Its Metaphors, New York: Farrar, Straus and Giroux, 1989. p. 46.

he encountered at a dinner party, "...the argument of many humane people like the doctor--forget the bigots--is that AIDS is a tragedy that primarily concerns people who insist on practices that endanger them: specifically, homosexuals engaging in anal intercourse and drug addicts so far gone that they share needles. Treat them compassionately but don't make a world-class disaster out of it. Pay more attention to people who do not bring their disease upon themselves."²⁹

What is clear is that the reasons for physicians' reluctance to care for patients with AIDS are complex and are intricately related. Fear of the disease is related to fear of death at a young age is related to unknown risks is related to exposure to alienated groups is related to their polluting capacity. Douglas states, "A polluting person is always in the wrong. He has developed some wrong condition or simply crossed some line which should not have been crossed and this displacement unleashes danger for someone."³⁰ It is a danger that has motivated some seroconverters to loudly exclaim that they were "innocent" recipients of the virus by blood transfusion to stave off any linkage with a risk group. Physicians sense and respond to this danger. But they are not alone in sensing and responding to this danger. The rest of the community has been

²⁹Rosenthal, A.M., "Doctor vs. Doctor," The New York Times, February 16, 1988, p. A21.

³⁰Douglas, Mary, Purity and Danger: An Analysis of Concepts of Pollution and Taboo, New York: Praeger Publishers, 1966. p. 113.

responding too.

The Response of the Community

In 1987 a Gallup Poll of 1,607 adults interviewed around the United States found the following: 45% agreed with the statement that "Most people with AIDS have only themselves to blame;" 33% said that employers should be able to dismiss employees with the AIDS virus; and 60% agreed with the statement "People with the AIDS virus should be made to carry a card to that effect."³¹ The idea that people with AIDS should be singled out and identified in some way so that they could be avoided or separated gained popularity for a time. Columnist William F. Buckley, Jr. reportedly called for universal screening and tattooing the forearms and buttocks of anyone positive for HIV.³² For a short time before it was withdrawn, the Louisiana House of Representatives "...passed a bill permitting the arrest and quarantine of any person with AIDS."³³ Local health officials in various states debated when and under what conditions it might be appropriate to isolate AIDS sufferers from the rest of society, and since 1985 at least nine states have gone so far as to amend

³¹"Public is Polled on AIDS," The New York Times, August 30, 1987, p. 20.

³²Brandt, Allan M., "AIDS: From Social History to Social Policy," Law, Medicine and Health Care, December 1986, 14:231-42. p.236.

³³"AIDS: A Diary of the Plague in America," People, August 3, 1987, p. 68.

or pass quarantine laws "...empowering health officials to isolate certain people with AIDS who endanger other peoples' health, but only as a last resort."³⁴ One report stated, "One sign of the times is that some people now speak in terms of quarantine, a charged word conjuring up frightening images of mass roundups and leper colonies. Senator Jesse Helms and Pat Robertson, the former television evangelist who [was] running for President, have suggested that quarantine may become necessary, although neither specified what he had in mind."³⁵ Musto states, "...quarantine is a response not only to the actual mode of transmission, but also to a popular demand to establish a boundary between the kind of people so diseased and the respectable people who hope to remain healthy."³⁶

There has been a widely held belief that AIDS is punishment brought on people for their own immoral behavior. Reportedly a Vatican spokesman, Archbishop John Foley, called the disease a "natural sanction" against immoral behavior.³⁷ A writer to the Ann Landers column said the following: "It is my hope that a cure for AIDS is not found. I also hope that it continues to infect individuals who are sexually promiscuous and those who

³⁴Lewin, Tamar, "Rights of Citizens and Society Raise Legal Muddle on AIDS," The New York Times, October 14, 1987, p. A1.

³⁵Lewin, p. B8.

³⁶Musto, David F., "Quarantine and the Problem of AIDS," The Milbank Quarterly, 1986, 64:97-117. p. 108.

³⁷Reinhold, Robert, "AIDS Issue at Fore as Pope Visits San Francisco Today," The New York Times, September 17, 1987. p. A33.

share dirty needles while injecting drugs. As long as people insist on giving this disease to themselves we should let them do it."³⁸ A Texas legislator reportedly did not feel that the disease was punishment enough, "...he was quoted as saying that AIDS programs were pouring money 'down a rat hole' and that infected prostitutes and drug abusers should be killed."³⁹

Many people have responded in peculiar and even outrageous ways to the perceived threat of AIDS. Two male college students now keep "...an 'AIDS index,' a one-to-ten scale by which they rate the likelihood of infection of their women friends."⁴⁰ During the trial of a man charged with assault against a woman who has AIDS, the judge "...ruled that evidence tainted with the blood of an AIDS victim could not be submitted as exhibits. Instead, photographs of a gun, handcuffs and clothing will be used.... Maloney found unacceptable the usual method of presenting blood-stained evidence in plastic bags."⁴¹ A prison inmate who tested positive for HIV was found guilty of assault

³⁸Landers, Ann, "Misanthrope Would Like to See Terrifying AIDS Run Its Course," New Haven Register, August 9, 1987. p. E3.

³⁹Lambert, Bruce, "In Texas, AIDS Struggle Is Also Matter of Money," The New York Times, January 5, 1990. p. A18.

⁴⁰Sachs, Jennifer, "Dangerous Decisions," The New Journal, December 4, 1987. p. 18.

⁴¹"Judge's Ruling Spreads AIDS Phobia," New Haven Register, September 22, 1987. p. 14.

with a deadly and dangerous weapon after biting two guards.⁴² Similarly, an HIV positive prisoner in Texas soon to be paroled after serving a term for robbery was "...resentenced to a life term after he was convicted of attempted murder for spitting in a guard's face."⁴³ A wife tried to sue her bisexual husband "...because she has developed an 'AIDS phobia' due to her husband's extramarital activities."⁴⁴ Perhaps the most outrageous statement reportedly was made by Philip Robertson, a Connecticut State Senator, after the passage of a bill to protect the confidentiality of people tested for AIDS. "'We're spending too much time protecting the rights of AIDS victims.' Robertson said. 'If someone's carrying around a deadly disease, I should know. And if I wish to discriminate I should discriminate.'"⁴⁵

One of the most disturbing events arising out of the atmosphere of fear and ignorance surrounding the AIDS epidemic that has been played out in towns all across the country is the barring from school of children infected with HIV. In Tennessee, one boy with hemophilia who was also positive for HIV reportedly "...was forced to ride a school bus alone and was quarantined by himself in a classroom following an incident in which some

⁴²"Deadly Weapon in AIDS Verdict Is Inmate's Teeth," The New York Times, June 25, 1987.

⁴³Lambert, p. A18.

⁴⁴"Can Wife Sue Spouse for Disease Phobia?" New Haven Register.

⁴⁵Lytle, Tamara, "Senate Wants AIDS Tests Confidential," New Haven Register, May 25, 1989. p. 1.

parents of classmates stoned the truck he was riding in to school, screaming, 'Kill him, kill him.'"⁴⁶ In Arcadia, Florida, three HIV positive boys with hemophilia were excluded from their school, and eventually their house was mysteriously burned. To the townspeople, "...the enemy was AIDS, a dark and sinister force that threatened their own children, no matter how many authorities assured them there was no risk in casual contact among school children."⁴⁷ One of the town physicians was quoted as saying, "'The parents are not convinced and can you blame them? Would you let your children play with a child with positive HIV? I have advised parents that from what I have read, HIV is not communicable through casual contact. But parents still fear exposure from the kids playing together.'"⁴⁸ Another local physician concurred, "'I know some parents have instructed their children not to come into contact with the Ray children.... And that's what I would tell my children.'"⁴⁹

Physicians as members of the community are subject to the same fears, rational and irrational, as the community. But they are also physicians. Is there something about being physicians

⁴⁶Gianelli, Diane M., "Panel's Chairman Urges Radical Change in U.S. War on AIDS," American Medical News, June 17, 1988. p. 32.

⁴⁷Nordheimer, Jon, "To Neighbors of Shunned Family, AIDS Fear Outweighs Sympathy," The New York Times, August 31, 1987. p. A1.

⁴⁸"Arcadia Physicians....," p. 34.

⁴⁹"Arcadia Physicians....," p. 34.

that ought to compel them to face their fear squarely and meet it by doing what they have trained to do, helping to overcome the pain and suffering caused by its source, AIDS? An editorial in The New York Times in response to physicians putting personal concerns above patient concerns in refusing to care for patients with AIDS states, "Any physician who holds that belief needs a new profession."⁵⁰ Former Surgeon General C. Everett Koop stated that such behavior threatens "'the ethical foundation of health care itself.'"⁵¹ This statement implies a role for physicians in maintaining that ethical foundation by caring for patients with AIDS, and it brings up the question of whether physicians have an ethical obligation to care for patients with AIDS. An answer to this question will be sought in the next chapter through an exploration of laws, regulations, ethical principles and historical precedent as they relate to the care of patients in the practice of medicine.

⁵⁰"When Doctors Refuse to Treat AIDS," The New York Times, August 3, 1987. p. A16.

⁵¹Boffey, Philip M., "Doctors Who Shun AIDS Patients Are Assailed by Surgeon General," The New York Times, September 10, 1987. p. 1.

Chapter 3: A Search for the Obligation in Tradition

I have a lot of friends who are scared. Those people that were supposed to be my friends before, now that I'm sick, stopped coming around. Well, I just won't be bothered with them.

I didn't know how my father would take it. He has foster kids and when I go down there I'm the big brother. I feel that it hit home down there because when my mother told him about my illness a few weeks ago and he called me he was very calm and cool. He said don't worry, everything will be all right. My father has never expressed his feelings. I was totally shocked. He told my mother that out of all the years I went down there on summer vacations, he said he never picked up on it, that I was gay. I know there's different things I might say or do, but he never knew. I always took for granted that he knew. But my step-mother knew. That bugs me--his calling regularly now. He and I were never close.

Medicine as Business

Do physicians have an ethical obligation to care for patients with AIDS? Physicians, lawyers and ethicists are finding that it is a question that probes at the essence of what it means to be a physician, and it is a very hard question to answer. It seems like it ought to be easy since physicians are in the business of treating patients with diseases. However, that is one of the problems. Is medicine a business that allows the physician total discretion for decision-making based on what the market can bear including the freedom to choose or reject patients at will and at whim? Or, is there some special moral dimension to the practice of medicine that calls forth standards of dedication over and above profit motive and free enterprise? These and related questions have filled professional journals for the past several years as answers have been unsuccessfully sought

through an exploration of present day medical ethics.

Emanuel asserts that the physician's obligation to treat patients with AIDS derives from his or her professional role. "The objective of a commercial enterprise is the pursuit of wealth; the objective of the medical profession is devotion to a moral ideal--in particular healing the sick and rendering the ill healthy and well."⁵² The fact of medicine as a commercial enterprise cannot be ignored, however. Health care costs are approaching 12 percent of the total gross national product. Furthermore, the changing economic structure of the institution of medicine encompasses every aspect of health care delivery. Starr writes,

The rise of a corporate ethos in medical care is already one of the most significant consequences of the changing structure of medical care.... Everywhere one sees the growth of a kind of marketing mentality in health care.... The organizational culture of medicine used to be dominated by the ideals of professionalism and voluntarism, which softened the underlying acquisitive activity. The restraint exercised by those ideals now grows weaker. The health center of one era is the 'profit center' of the next.⁵³

This "marketing mentality" has a direct bearing on both the decisions a physician may make in deciding whom to treat and on the nature of the physician-patient relationship. Patients with AIDS are destined for a long drawn-out course of devastating illnesses requiring very expensive sorts of tests and treatment.

⁵²Emanuel, Ezekiel J., "Do Physicians Have An Obligation to Treat Patients with AIDS?" The New England Journal of Medicine, June 23, 1988, 318: 1686-90. p. 1686.

⁵³Starr, Paul, The Social Transformation of American Medicine, New York: Basic Books, Inc., 1982. p. 448.

The General Accounting Office, an investigative arm of Congress, reportedly estimates that the number of people developing AIDS by 1991 could reach 480,000.⁵⁴ Fineberg states that a recent report of the U.S. Public Health Service predicts 450,000 cases of AIDS diagnosed by the end of 1993 and projected personal medical costs for patients with AIDS during 1991 of between \$4.5 and \$8.5 billion.⁵⁵ Patients with AIDS do not have the resources to cover those costs. About 40% of the 50,000 people presently diagnosed with AIDS rely on Medicaid to cover their health care costs, however, nearly half of the state Medicaid programs will not pay for one or more of the drugs commonly used to treat AIDS. Furthermore, many states will not cover those same drugs for people who are HIV positive but have not yet developed AIDS.⁵⁶ One year's worth of zidovudine, AZT, can cost \$8000. Very few patients with AIDS receive Medicare assistance because it takes two years to qualify and most do not survive that long.⁵⁷ Even when patients do have private health insurance, most policies pay only a fraction of the cost of drugs prescribed outside the hospital and often will not cover at all the alternative types of

⁵⁴"Forecasts of AIDS Fall Short, U.S. Study Says," The New York Times, June 26, 1989. p. B5.

⁵⁵Fineberg, Harvey V., "The Social Dimensions of AIDS," Scientific American, October 1988:128-34. p. 134.

⁵⁶"Medicaid's Hodgepodge on AIDS," The New York Times, May 25, 1989. p. B18.

⁵⁷Rogers, David E., "Federal Spending on AIDS--How Much Is Enough?" The New England Journal of Medicine, June 15, 1989, 320:1623-1624. p. 1623.

care needed by patients with AIDS such as home and hospice care.⁵⁸ To say the least, it is not worth a private physician's economic while to take on this sort of burden.

AIDS and the Law

Nor is a physician legally obligated to take on this burden. American common law upholds the principles of individual liberty and economic freedom, and when applied to medicine, this concept has been called the "no duty rule."⁵⁹ Statutory law has been equivocal on this issue. Annas bluntly states,

...a physician is not obligated to treat any particular patient in the absence of a consensual doctor-patient relationship. In the absence of a prior agreement or a statutory or regulatory prohibition, physicians (like other citizens) can, in deciding whether to accept patients, discriminate among them on the basis of all sorts of irrelevant and invidious criteria; from race to religion, to personal appearance and wealth, or by specific disease, like AIDS.⁶⁰

There are two exceptions to the physician's freedom to refuse to treat patients. One exception is in the case of physicians working in an emergency room who must treat all patients who arrive with a medical emergency. This right to emergency health care in an emergency room is the only legal right to health care guaranteed anyone in this country regardless

⁵⁸Fineberg, p. 134.

⁵⁹See Annas and Banks for further explanation of the "no duty rule", (infra notes 60 and 62 respectively).

⁶⁰Annas, George J., "Legal Risks and Responsibilities of Physicians in the AIDS Epidemic," The Hastings Center Report, April/May, 1988; 18:26-32. p.26.

of one's illness or condition. Massachusetts is the only state with licensing regulations further requiring physicians to treat patients in an emergency situation outside of the hospital as long as the physician has the appropriate training.⁶¹ The other exception is in the case of a prior consensual physician-patient relationship. The law recognizes a physician-patient relationship based on contract, that is, even from the time a patient phones a doctor's office to make an appointment for a specific purpose, there is an implied contract between the two parties. This contractual relationship then imparts to the physician the duty to treat. However, this contract neither guarantees future care for a new illness, nor does it require a physician to make an appointment with a given patient in the first place.⁶²

Annas draws a distinction between treating patients with AIDS or AIDS-related complex (ARC) versus treating patients with HIV. "Treating an individual with AIDS or ARC involves the knowledge and skill needed to treat a specific disease; treating an HIV-infected patient involves knowing what precautions to take to avoid infection while treating a different, usually unrelated condition."⁶³ Therefore, a physician may claim that he or she

⁶¹Massachusetts Board of Registration in Medicine, 243 Code of Massachusetts Regulations 2.07 (10), cited in Annas, p. 27.

⁶²Banks, Tauna Lovell, "The Right to Medical Treatment," in H. Dalton, S. Burris, and the Yale AIDS Law Project, eds., AIDS and the Law, New Haven: Yale University Press, 1987. p. 176.

⁶³Annas, p. 27.

lacks the specialized knowledge to care for patients with AIDS or ARC. It may be more difficult to find an excuse not to care for patients with HIV especially if the treatment given is unrelated to HIV status, for example, treatment of pregnancy or hypertension. It is important to point out, however, that this distinction is lost in the light of drug treatments such as AZT or newer treatments which may be found to control the effects of the virus or prolong the asymptomatic period. It now behooves any physician whose patient is or may become HIV positive to be aware of new therapies. In any case, a physician may not abandon a patient once a "contractual" relationship has been established until reasonable notice has been given to the patient to locate appropriate alternative care.⁶⁴

Other contractual agreements to which physicians are a party may also obligate them to treat patients with AIDS. For example, physicians working for Health Maintenance Organizations (HMOs) or hospitals must abide by the rules and regulations of those institutions and are not free to make independent decisions to refuse to care for certain patients. The Associated Medical Schools of New York which represents the state's 13 public and private medical schools issued a strong policy statement on physicians' "most fundamental responsibility" to treat patients with AIDS regardless of risk. "'Communicable diseases have traditionally called for sacrifice and courage from the medical

⁶⁴Annas, p. 27.

community.... In addition, medical schools and academic health centers have a special duty to fight not only the disease itself but the fear and misinformation surrounding the disease.'" Students or physicians refusing to treat patients with AIDS would be subject to dismissal.⁶⁵ An alternate approach has been taken by Yale-New Haven Hospital which in 1987 adopted a policy recommended by its Bioethics Committee that makes the clinical departments, but not individual physicians, responsible for assuring adequate care for patients with AIDS. The policy states,

It is not the intent of these recommendations to create inflexible positions or to mandate action in individual cases. As long as each Department accepts its obligation to provide a full complement of personnel to carry out its share of the service, it may not be necessary, other than by the powers of moral persuasion, to put pressure upon unwilling personnel who are otherwise valuable members of their Departments.⁶⁶

A physician may be legally bound to treat patients with AIDS under federal or state antidiscrimination legislation. The Rehabilitation Act of 1973 prohibits discrimination on the basis of handicap in federally assisted programs. In 1987 the concept of handicap was applied by the U.S. Supreme Court to tuberculosis, an infectious disease, but interestingly in a

⁶⁵Sullivan, Ronald, "13 Medical Colleges Say Staff Must Treat AIDS," The New York Times, December 9, 1987. p. B3.

⁶⁶"Responsibilities to Patients Who Have or Are at Risk for AIDS Virus Infection," Yale-New Haven Hospital, March 23, 1987. p. 6.

footnote the Court stated that the case was not about AIDS.⁶⁷ Forty-seven states have similar antidiscrimination laws and two-thirds of them include AIDS as a handicap.⁶⁸ The Massachusetts Commission Against Discrimination has become involved in a case against a dentist who refused to treat a patient with AIDS. One Massachusetts attorney states,

A physician who refuses to treat a patient out of fear of AIDS contamination, whether or not the patient reveals a positive infection, runs the risk that the patient, or an AIDS advocacy group, will file discrimination charges. The plaintiff must prove that the physician refused the treatment because of the patient's handicap or because the patient was "regarded as having" AIDS, clinical evidence notwithstanding. But such proof is relatively easy to obtain and can be gleaned by examining the physician's recent records for a pattern of curtailed treatment of other patients with similar histories.⁶⁹

The federal Civil Rights Act of 1964 prohibits discrimination on the basis of race, religion or national origin in places of public accommodation. Some states have similar statutes and include handicap as a basis of discrimination.⁷⁰ Places of public accommodation may be interpreted to include doctors' offices, hospitals and nursing homes so that refusing to treat a patient with AIDS would be illegal. However, as Annas points out, "It will...be difficult to define private doctors'

⁶⁷School Board of Nassau County, Florida v. Arline, 107 Supreme Court 1123 (1987). p. 1128.

⁶⁸Banks, p. 178.

⁶⁹Schwartz, Harvey and Gray, Alec, "Treating Patients with AIDS: Can You Say No?" Massachusetts Medicine, Sept/Oct, 1987, 2:39-43. p. 41.

⁷⁰Banks, p. 178.

offices as places of 'public accommodation' for the purposes of antidiscrimination laws. Private physicians' offices are generally not open to the public without appointment; and even then access is generally limited to certain diseases or categories of patients that the physician is capable of treating and agrees to treat in advance."⁷¹ Several California cities have laws specifically prohibiting discrimination against people with AIDS, and Wisconsin has a law prohibiting discrimination based on sexual preference so that it is illegal to refuse to treat gay people for fear that as members of a high risk group they may transmit HIV.⁷²

Physicians may or may not be required to care for patients with AIDS by state licensing boards which have statutory authority to regulate the practice of medicine. While the Connecticut board has considered the issue, the present regulations do not address it. The Massachusetts Board of Registration in Medicine in June, 1988, adopted AIDS Guidelines which state,

Licensed professionals have a duty to care, treat or provide services to persons with AIDS, ARC or HIV-infection. Exceptions to this obligation may occur in clearly defined, unusual instances but as a general rule, all licensed professionals should be aware of their affirmative duty to treat, care for or deliver services to persons with AIDS, ARC or HIV-infection.⁷³

⁷¹Annas, p. 29.

⁷²Banks, p. 178.

⁷³Massachusetts Board of Registration in Medicine, AIDS Guidelines.

Stated possible exceptions to this obligation "in unusual cases" are a pregnant physician who may be exposed to cytomegalovirus, and a physician who is "... not equipped to manage certain clinical manifestations of AIDS in which case professionals should still offer non-specialized services."⁷⁴ The guidelines specify that violations may be dealt with by "remedial AIDS education," or "more stringent sanctions might be imposed as appropriate."

Florida requires mandatory continuing education on AIDS for license renewal. The Arizona Board of Medical Examiners, on the other hand, has stated that their licensees may refuse continued treatment to patients with AIDS. The Board's rationale is based on the following premises: First, some physicians, because of personal reasons, may feel uncomfortable treating patients with communicable diseases such as AIDS or hepatitis, and, therefore, might not provide adequate care. Second, many physicians at the time the policy was adopted lacked a "true understanding of communicable diseases, such as AIDS," and, therefore, it would be in the patients' best interest to transfer them to others with more expertise.⁷⁵

It is clear that we cannot look to the law for an obligation to care for patients with AIDS; "...individual physicians have no legal duty to treat except in specific situations" of which HIV

⁷⁴Massachusetts Board of Registration in Medicine.

⁷⁵Personal communication with Douglas N. Cerf, Executive Director, Board of Medical Examiners State of Arizona.

positivity is not one.⁷⁶ Furthermore, ethical behavior cannot be realistically legislated. As Annas points out, the law cannot force people to be courageous or virtuous.⁷⁷ A legal obligation is not the same thing as an ethical obligation, and, in fact, legal remedy as a response to ethical omission often mandates ill will. When the fundamental ethical foundation of such regulations is not understood to stand for itself as a reason to behave a certain way, in which case the regulations may not be necessary in the first place, the regulations may be perceived as punitive. Since an answer to whether or not physicians have an ethical obligation to care for patients with AIDS cannot be found in the law, it will have to be sought elsewhere.

AIDS and the Profession

As stated earlier, Emanuel asserts that the physician's obligation to treat derives from his or her professional role. "When a person joins the profession, he or she professes a commitment to these ideals and accepts the obligation to serve the sick. It is the profession that is chosen. The obligation is neither chosen nor transferable; it is constitutive of the professional activity."⁷⁸ Grounding this obligation to treat in

⁷⁶Annas, p. 31.

⁷⁷Annas, George, "Not Saints, But Healers: The Legal Duties of Health Care Professionals in the AIDS Epidemic," American Journal of Public Health, July 1988, 78:844-49. p. 844.

⁷⁸Emanuel, p. 1686.

the profession is like saying that a doctor has to take care of patients with AIDS because he or she is a doctor. This circular reasoning goes nowhere unless there are qualities and traditions particular to the profession of medicine that mandates this obligation in the face of a tradition of common law that does not. Furthermore, while it may be evident that the medical profession as a whole has an obligation to provide for the care of patients with AIDS because there is no other profession competent to do so, it is not as evident that the obligation extends to individual members of that profession. This "social contract approach" holds that physicians provide service of ministering to the sick and vulnerable and in exchange gain monopolistic privileges over the practice of medicine. Monopolistic privileges incur a duty on the part of the profession but not necessarily on individuals within the profession to insure that the sick are cared for.⁷⁹

Arras believes that the social contract approach is consistent with the voluntaristic notion that patients with AIDS will get taken care of by those physicians who want to take care of them and not by those who do not. It breaks down only if the needs of the patients are not met, and, in fact, harm is done due to the failure to provide proper care. Arras easily foresees such harm coming about from delays in treatment resulting from

⁷⁹Arras, John D., "The Fragile Web of Responsibility: AIDS and the Duty to Treat," The Hastings Center Report, April/May 1988, 18:10-20. p. 11.

referring patients elsewhere, inadequate or substandard care resulting from lack of commitment of resources to an unpopular cause, and the very rejection and stigmatization of patients by the physicians choosing not to treat them. Furthermore, if AIDS becomes less confined to large cities with their greater variety of health care institutions including some urban hospitals with AIDS Care Units and creeps into rural America with its fewer resources to face this problem, the implications become even graver should health care workers not understand their individual obligations to care for these patients. Under these circumstances, "...the social contract through the conditions of licensure would justify the imposition of an individualized duty to treat."⁸⁰ However, as already seen, while licensure may compel individuals to treat, it does not compel the moral obligation. The obligation to treat can be grounded in profession only if the profession itself is clear and unambiguous about that obligation.

The position of the medical profession on a physician's obligation to care for patients with AIDS may be understood to an extent by examining the principles and codes of ethical conduct put forward by state and national professional organizations. While not all physicians belong to these organizations and presumably not all subscribe to these so-called codes, as Freedman states, "On a descriptive level, they may represent an

⁸⁰Arras, p. 12.

expression of the profession's own conception of the ethical obligations of its members...."⁸¹ It is clear from these codes and ethical statements that the medical profession is ambivalent in its stand on this issue.

The American Medical Association (AMA) adopted its first Code of Medical Ethics in 1847. This code was based on the already existing codes of the New York State Medical Society and the Baltimore Medical Society which were both based on the code of medical ethics published by Dr. Thomas Percival in 1803. The original AMA code consisted of three chapters: I. Of the duties of physicians to their patients, and of the obligations of patients to their physicians; II. Of the duties of physicians to each other, and to the profession at large; III. Of the duties of the profession to the public, and of the obligations of the public to the profession. Thus, this code is a catalogue of duties and obligations unilaterally put forward by the profession but dictating norms of behavior for physicians and patients alike. It differentiates between collective group obligations (the profession, the public) and individual obligations (physicians, patients). It is important in its intent to publicly voice acknowledgement of a tie between the moral underpinnings of medicine to a broader ethical rights/duties domain. The introduction to the code states, "Medical ethics, as

⁸¹Freedman, Benjamin, "Health Professions, Codes, and the Right to Refuse to Treat HIV-Infectious Patients," The Hastings Center Report, April/May 1988, 18:20-25. p.21.

a branch of general ethics, must rest on the basis of religion and morality. They comprise not only the duties, but, also the rights of a physician: and, in this sense, they are identical with Medical Deontology...."⁸²

Duties of Physicians to Their Patients loftily proclaims,

A physician should not only be ever ready to obey the calls of the sick, but his mind ought also to be imbued with the greatness of his mission, and the responsibility he habitually incurs in its discharge. Those obligations are the more deep and enduring, because there is no tribunal other than his own conscience, to adjudge penalties for carelessness or neglect.⁸³

For the first time in any professional code, Duties of the Profession to the Public includes the following: "...and when pestilence prevails, it is their duty to face the danger, and to continue their labours for the alleviation of the suffering, even at the jeopardy of their own lives."⁸⁴ Here is found documentation of a thread of professional commitment that calls for even self-sacrifice. It is a thread that runs in and out of the tapestry of the practice of medicine. While the collective profession has the duty to act in times of "pestilence", however, it is not clear whether or not the individual does. That may be left up to him and his conscience. This chasm between professional responsibilities and requirement for an individual

⁸²American Medical Association, "Excerpts from the Proceedings of the National Medical Convention of May 1846 Regarding Creation of the Code of Medical Ethics." p. 1.

⁸³"Excerpts...", p. 10.

⁸⁴"Excerpts...", p. 21.

response can be seen to widen over the years.

In 1903, the title was changed from "Code" to "Principles of Medical Ethics" and mention of the physician's conscience was removed. The tone of the revision of 1912 changes entirely and the statement of The Physician's Responsibility is as follows:

A profession has for its prime object the service it can render to humanity; reward or financial gain should be a subordinate consideration. The practice of medicine is a profession. In choosing this profession an individual assumes an obligation to conduct himself in accord with its ideals.⁸⁵

Under Duties of the Profession to the Public it states, "When an epidemic prevails, a physician must continue his labors for the alleviation of suffering people, without regard to the risk to his own health or life or to financial return."⁸⁶ The plural of the 1903 version "...continue their labors" has been replaced with "a physician must continue his labors," appearing to individualize this duty. However, in 1912 the following statement first appears:

A physician is free to choose whom he will serve. He should, however, always respond to any request for his assistance in an emergency or whenever temperate public opinion expects the service. Once having undertaken a case, a physician should not abandon or neglect the patient because the disease is deemed incurable; nor should he withdraw from the case for any reason until sufficient notice of a desire to be released has been given the patient or his friends to make it possible for them to secure

⁸⁵"Principles of Medical Ethics of the American Medical Association," Chicago: American Medical Association Press, 1912. p.3.

⁸⁶"Principles...", 1912, p. 21.

another medical attendant.⁸⁷

Therefore, it was the duty of the profession to provide care in an epidemic. While the 1912 version of the Principles appears to particularize this duty to individual physicians by its use of singular pronouns, the new statement affirming a physician's right to choose his patients modifies the epidemic duty. Yes, he should "continue his labors", but he may choose for whom he wishes to labor. It is this last statement based on the notion of medicine as exemplar of the free enterprise system and to which the AMA has fervently clung throughout the years that has allowed physicians to argue that there is no obligation to treat patients with AIDS. This thread of personal choice appears to overshadow the thread of personal sacrifice. While this 1912 statement qualified the physician's freedom to choose patients with "except in an emergency or whenever temperate public opinion expects the service", this qualification lasted only until 1957.

The statement on abandonment is consistent with the legal interpretation of a contractual physician-patient relationship wherein once a relationship has begun, the physician may not end it without seeing to it that the patient at least has sufficient notice if not sufficient treatment. It is interesting to note that the physician is not required to notify the patient, but may notify his friends. This rather broad interpretation of the object of the physician's duty was expanded in 1947 to "the

⁸⁷"Principles...", 1912, pp. 4-5.

patient, his relatives or his responsible friends."

For a very brief time in the revision of 1947, the Principles included the following statement under The Physician's Responsibility:

The profession of medicine, having for its end the common good of mankind, knows nothing of national enmities, of political strife, of sectarian dissensions. Disease and pain the sole conditions of its ministry, it is disquieted by no misgivings concerning the justice and honesty of its client's cause; but dispenses its peculiar benefits, without stint or scruple, to men of every country, and party and rank, and religion, and to men of no religion at all.⁸⁸

Coming around World War II, this statement seemed to affirm a commitment of an idealistic profession able to rise above the mundane demands of politics and the forces that are divisive among people. It was a short-lived commitment, however, when in 1957 the Principles were streamlined to ten short statements called "Sections". Gone also was any mention of physicians' duties in time of pestilence or epidemic.

In 1980, the Principles were revised for the last time and honed down to seven brief legalistic statements. The preamble states, "As a member of this profession, a physician must recognize responsibility not only to patients, but also to society, to other health professionals, and to self." (emphasis added)⁸⁹ Implied here is the social contract between the

⁸⁸"Principles of Medical Ethics of the American Medical Association," Chicago: American Medical Association, 1949. p. 4.

⁸⁹"American Medical Association Principles of Medical Ethics," 1980.

profession and society. In fact, Section VII extends the responsibility of a physician to "participate in activities contributing to an improved community." Even though "a physician" as a member of the profession must recognize this responsibility, Section VI staunchly declares, "A physician shall, in the provision of appropriate patient care, except in emergencies, be free to choose whom to serve, with whom to associate, and the environment in which to provide medical services."⁹⁰ At the same time the profession wishes to assert recognition of an obligation to act on behalf of society, it holds on tight to the individual freedom of choice of the members of the profession.

This tension between individual choice and societal obligation led to confusion and contradictions in the AMA's early statements directed at the specific question regarding a physician's obligation to treat patients with AIDS. In its 1986 "Statement on AIDS", the Council on Ethical and Judicial Affairs of the American Medical Association held the following:

Physicians and other health professionals have a long tradition of tending to patients afflicted with infectious disease with compassion and courage. However, not everyone is emotionally able to care for patients with AIDS. If the health professional is unable to care for a patient with AIDS, that individual should ask to be removed from the case. Alternative arrangements for the care of the patient must be made.⁹¹

⁹⁰"Principles...", 1980.

⁹¹American Medical Association, Council on Ethical and Judicial Affairs, "Statement on AIDS," December, 1986.

This one statement both reminisces about a tradition of compassion and courage while it excuses physicians from taking care of patients with AIDS on the grounds of emotional instability. Of course, these same physicians are presumably emotionally capable of treating patients with cancer, patients with schizophrenia, and patients who are terminally ill. It is difficult to imagine this statement seriously receiving the sanction of the AMA, but it did. However, this statement was replaced by one taking a somewhat different stance a year later.

In its 1987 statement, the AMA upheld the right of patients with AIDS to be free from discrimination and went on to affirm the following:

A physician may not ethically refuse to treat a patient whose condition is within the physician's current realm of competence solely because the patient is seropositive. The tradition of the American Medical Association, since its organization in 1847, is that: "when an epidemic prevails, a physician must continue his labors without regard to the risk to his own health...." That tradition must be maintained. A person who is afflicted with AIDS needs competent, compassionate treatment. Physicians should respond to the best of their abilities in cases of emergency where first aid is essential, and physicians should not abandon patients whose care they have undertaken.⁹²

This last exhortation is, of course, consistent with the requirements of statutory law. For the first time since 1947, however, this statement mentions the sustenance of an obligation to treat in the face of personal risk.

The AMA statement goes on to interpret Section VI of the

⁹²AMA Council on Ethical and Judicial Affairs, "Ethical Issues Involved in the Growing AIDS Crisis," December 1987. (Revised: September 1988)

Principles of Medical Ethics in relation to AIDS.

Principle VI of the 1980 Principles of Medical Ethics states that "A physician shall in the provision of appropriate patient care, except in emergencies, be free to choose whom to serve, with whom to associate and the environment in which to provide medical services." The Council has always interpreted this Principle as not supporting illegal or invidious discrimination.... Thus, it is the view of the Council that Principle VI does not permit categorical discrimination against a patient based solely on his or her seropositivity. A physician who is not able to provide the services required by persons with AIDS should make an appropriate referral to those physicians or facilities that are equipped to provide such services.⁹³

This statement no longer specifically limits inability to that of emotional etiology, but it does continue to offer an out to physicians who "are not able" to take on patients with AIDS. Another major difference between this statement and the earlier one is that this statement attempts to modulate the AMA's stance on the supremacy of the physician's individual choice regarding particular patients. Now it is refined to specifically exclude blatant discrimination.

But what might make a physician "not able to provide the services required by persons with AIDS?" One AMA Council member commented, "A physician doesn't have to care for AIDS if the disease process is out of his spectrum of knowledge but, for example, a surgeon should not refuse to operate because a patient has AIDS."⁹⁴ What this comment seems to mean is that a physician may not be in a position to treat the manifestations of a

⁹³AMA Council, 1987.

⁹⁴"Unethical to Refuse to Treat HIV-Infected Patients, AMA Says," American Medical News, Nov. 20, 1987. pp. 1 and 43.

patient's AIDS because of the nature of his or her specialty, however, the physician should not refuse to treat the patient within the confines of that specialty. Naturally an ophthalmologist does not treat renal disease, but he or she can treat eye disease in a patient with AIDS nephropathy. In any specialty, the concurrence of AIDS with other disease may affect the way that other disease is treated just as the concurrence of any two diseases may. For example, there may be interactions between drugs that a patient is receiving for two disease processes. Physicians routinely are faced with the task of acquiring recent information on disease processes. These sorts of considerations are nothing new, and patients with AIDS should not, in fact, except for extraordinary circumstances, present a knowledge-based excuse for not treating patients. The AMA statement does not clearly drive home this point.

Some state medical associations have adopted their own policies on physicians' responsibilities in the face of AIDS. For example, Arizona's policy states, "ArMA [Arizona Medical Association] feels that it is the responsibility of every physician to become educated in and share the responsibility of care of AIDS patients.... Should a physician be unable to treat such patients, the physician must refer each patient to one who will provide the necessary care...."⁹⁵ Again, it is not clear

⁹⁵The Arizona Medical Association, "AIDS: Position of the Arizona Medical Association Regarding Acquired Immune Deficiency Syndrome," 1988.

what might make a physician unable to care for patients with AIDS. The statement is purposefully vague so as not to infringe on a physician's free choice of patients even if that choice is based on prejudice. This statement does not even go as far as that of the AMA which discourages discrimination. The Arizona Medical Association goes on to tell physicians that they must inform the physicians to whom they refer patients with AIDS of the patient's diagnosis. It does not offer any guidance about what to do should the referral physician also be "unable to treat such patients."

The Texas Medical Association (TMA) has adopted a simply stated policy. A physician may either accept responsibility for the care and treatment of patients with AIDS or HIV or "infection with any other probable causative agent of AIDS," or the physician shall refer the patient to another physician who will accept such responsibility.⁹⁶ Dr. James Mann, chairman of TMA's Board of Counselors reportedly commented, "'We didn't agree that a physician who diagnoses AIDS is mandated to treat the patient.... I don't think it can be called discrimination when it's a matter of a guy laying his health and career on the line. A young man [sic] may spend 15 years of his life getting medical training and risk his life treating disease....'"⁹⁷

Other professional organizations have also taken a stand on

⁹⁶Texas Medical Association, Policy Manual, 1988. p. 1.

⁹⁷"TMA Policy Lets MDs Refuse AIDS Patients If They Refer," American Medical News, December 4, 1987. p. 39.

this issue. In 1986 the American College of Physicians and The Infectious Diseases Society of America issued a joint statement. Their position was to "...urge all physicians, surgeons, nurses, other medical professionals, and hospitals to provide competent and humane care to all patients, including patients critically ill with AIDS and AIDS-related conditions. Denying appropriate care to sick and dying patients for any reason is unethical."⁹⁸ While the choice of the word "urge" does not carry much force, the stated rationale for this position carried more conviction.

Health care workers who have the primary responsibility for a patient's well-being must provide high-quality non-judgmental care to their patients, even at the risk of contracting a patient's disease. Physicians and nurses are charged by the ethics of their healing profession to treat patients with all forms of sickness and disease.⁹⁹

In 1988 these organizations took an even stronger stand when they said,

Refusal of a physician to care for a specific category of patients, such as patients who have AIDS or who are HIV-positive, for any reason, is morally and ethically indefensible. The practice of medicine is a societal trust and carries with it a societal responsibility. If medicine wishes to retain its respected status as the healing profession, we must continue to provide the best possible care to our patients, regardless of personal risk. To do less threatens the very nature of the patient-physician relationship, makes a mockery of our professional heritage,

⁹⁸Health and Public Policy Committee, American College of Physicians; and The Infectious Diseases Society of America, "Acquired Immunodeficiency Syndrome," Annals of Internal Medicine, April 1986, 104:575-81. p. 576.

⁹⁹Health and Public Policy Committee, 1986. p. 576.

and violates the very essence of being a physician.¹⁰⁰

This statement goes beyond appealing to physicians to behave well out of obligation to some vague notion of professional allegiance and touches on something undefined but deeper. To refuse to treat violates the essence of being a physician and does damage to the patient-physician relationship. The importance of this concept will be examined and discussed further in Chapter 6. There are two other concepts that have been introduced by these statements that need attention first. One is professional tradition or heritage referred to in this last statement and in the 1987 statement of the AMA. The other is the inclusion of nurses in the 1986 urgings of the American College of Physicians and the Infectious Diseases Society of America to provide competent and humane care for patients with AIDS. First, let us consider nurses. Nurses had already addressed the problem for themselves.

In 1986, the American Nurses' Association (ANA) developed a statement entitled "Statement Regarding Risk V. Responsibility in Providing Nursing Care." In general, the ANA statement attempts to evaluate personal risks associated with caring for patients with infectious diseases including but not limited to AIDS in light of nursing responsibility. Freedman discusses the extent

¹⁰⁰Health and Public Policy Committee, American College of Physicians; and the Infectious Diseases Society of America, "The Acquired Immunodeficiency Syndrome (AIDS) and Infection with the Human Immunodeficiency Virus (HIV)," Annals of Internal Medicine. March 1988, 108:460-69. p. 462.

to which they succeed in so doing.¹⁰¹ However, what is more interesting is a comparison of parts of the 1986 statements of the two professional organizations, the AMA and the ANA.

Recall that the AMA statement allowed for refusal to care for patients with AIDS on the grounds of emotional inability. In contrast, the ANA states, "Nursing, as nursing, creates a special relationship between nurse and patient, with special duties for the nurse. The nurse is not a 'stranger' and thus is not at liberty to walk away from those in need of nursing assistance."¹⁰² "Nursing, as nursing...." Nursing finds in its rich context an ethos of relationality wherein the nurse is not a stranger to the patient and from which sense of moral community flourishes the obligation to stay and care for patients with AIDS. Also, in stark contrast to the AMA Principle's Section VI with its affirmation of the physician's freedom to choose whom to treat is the statement that a nurse is "not at liberty to walk away." Seemingly, this phrase represents a lack of freedom of choice. However, here choice is tempered by professional commitment, very similar to that thread first found in the 1847 AMA Code of Ethics, a concept to which we shall return in Chapter 7. Finally, the nurse not at liberty to walk away is an image that stands in contradistinction to the documented examples of

¹⁰¹Freedman, p. 22.

¹⁰²American Nurses' Association Committee on Ethics, "Statement Regarding Risk Versus Responsibility in Providing Nursing Care," Ethics in Nursing: Position Statements and Guidelines, 1986. p. 6.

physicians fleeing in times of pestilence. It is time to turn to that professional tradition and history and see how they relate to the question of whether physicians have an obligation to care for patients with AIDS.

Another way of looking at a physician's obligation in terms of profession and professional role is to examine actions of physicians in past major episodes of infectious disease. What has been the historical response of physicians in times of personal risk? What is the professional tradition passed from one generation of physicians to another? The best that can be said is that medicine presents a mixed tradition marbled with strands of exemplary courage and mired with moments of cowardice. If all that was found was a tradition of dedication and courage, it might be said that a physician's obligation to treat is clearly grounded in historical precedent.

It is difficult, however, to evaluate the meaning of physicians fleeing from plagues and pestilence since, as Fox points out, "Much of the evidence about physicians abandoning patients during epidemics, when read in context, furnishes no proof that such conduct violated prevailing ethical norms."¹⁰³ Furthermore, some physicians who stayed to care for patients during epidemics did so out of opportunity for personal profit rather than for ethical motives.

¹⁰³Fox, Daniel M., "The Politics of Physicians' Responsibility in Epidemics: A Note on History," The Hastings Center Report, April/May 1988, 18:5-10. p. 6.

Amundsen attempts to put the deeds of physicians during times of plague in the late Middle Ages into ethical perspective. He does so by analyzing the plague tractates, papers written during the years of plague by physicians describing their own and others' actions. He begins by pointing out that when Galen fled Rome during the plague of the second century, it could not have been an act evaluated by standards of professional ethical conduct because there were none at the time. The physician of the day was

...bound to his fellow men by no obligation, however ill-defined, other than by whatever ethical principles he might choose to adopt.... At no time were physicians required to swear any oath or to accept and abide by any formal or informal code of ethics. Moreover, the physician sold his services at his own discretion to those who asked and paid for treatment; he exercised his art as he wished.¹⁰⁴

During the early Middle Ages, many physicians were guided by a sense of obligation derived from religion, and it was not until the late Middle Ages that there appeared an appreciation on the part of physicians and non-physicians alike for a professionally derived medical deontology. During the time, medicine was organized around guilds whose purposes were fraternal, political and commercial. The guilds established monopolistic control over a craft and attempted to ensure a high standard of competence and ethical conduct. The entrance into the guilds was limited, and "It was not unusual for the individual, before being admitted to

¹⁰⁴Amundsen, Darrel W., "Medical Deontology and Pestilential Disease in the Late Middle Ages," Journal of the History of Medicine, October 1977:403-421. p. 405.

the exclusive circle of practitioners, to be required to swear that he would, for example, faithfully care for the ill of the city or region."¹⁰⁵ Thus, out of professional identity began to emerge a sense of ethical responsibility.

Amundsen goes on to detail physician behavior during the great plagues of Europe in the Middle Ages. Some physicians stayed and dedicated themselves to treating the sick and dying all the while concerned with precautions to be followed to prevent their own exposure to the source of deadly disease. One physician of the time left a sixteen point list of precautions to be followed some of which reads alarmingly similar to modern day body fluid precautions. On the other hand, some physicians fled from the plague choosing personal safety over professional obligation. Amundsen points out, however, that this act should be judged bearing in mind that there was a very strong tradition dating back to ancient classical medicine that it was wrong to treat a patient whom the art of medicine could not help.

Unable to find historical grounding for a physician's obligation to treat, Fox finds in the plague doctor a model for fulfilling the general societal obligation of medicine to provide care to the victims of an epidemic. Plague doctors were physicians who contracted to provide care in return for a sizeable remuneration of salary, living expenses and, sometimes, a promise of citizenship. Therefore, they acted more out of a

¹⁰⁵ Amundsen, p. 408.

desire for personal profit than an expression of professional ideals. Fox sees something similar operating today when doctors who agree to care for patients with AIDS concentrate in AIDS units or in large city hospitals. Fox regards their rewards to be access to research funds or academic status. However, on the contrary, many physicians who bear the brunt of this effort, for all their dedication, are often more likely considered to be doing inferior work.¹⁰⁶ The attitude of their physician peers is, better you than me.

Zuger and Miles look at physician behavior in past epidemics in a search for "...a coherent professional ethic governing the care of human immunodeficiency virus (HIV)-infected persons...."¹⁰⁷ They begin by noting that AIDS has little in common with past epidemics in terms of personal risk posed to physicians since the risks of AIDS have been evaluated and can be controlled using proper precautions unlike the largely unknown risks of past infections. After a detailed overview of both historical professional conduct and codes, they conclude the following:

These examples illustrate the difficulties of grounding a professional ethic for the care of HIV-infected persons exclusively in historic precedent and existing ethical codes. First, the professional tradition has not been consistent: in all epidemics some physicians have fled and

¹⁰⁶ Personal communication with a physician in charge of a city hospital AIDS care program.

¹⁰⁷ Zuger, Abigail and Miles, Steven H., "Physicians, AIDS, and Occupational Risk: Historic Traditions and Ethical Obligations," Journal of the American Medical Association, October 9, 1987, 258:1924-28. p. 1924.

some have stayed, in most cases impelled by individual conscience rather than professional ethic. Second, past epidemics resemble AIDS very little, save only in the fear they have provoked among some physicians. Finally, our ethical language differs enormously from that of past centuries. Respect for individual civil rights and autonomy now protects the discretionary freedom of physicians as well as of their patients.¹⁰⁸

AIDS and the Hippocratic Oath

In a final attempt to locate a physician's obligation to treat in tradition, the Hippocratic Oath as a source of that obligation should be considered. Generations of graduating medical students have sworn the Hippocratic Oath as they made the transition to physician. What can be found in the Oath in support of a tradition to care for patients in the face of personal risk?

Nowhere in the Oath is there mention of an explicit obligation to care for sick patients. The Oath, which Edelstein traces to the fourth century B.C., is really written in two parts. First, the physician's duties toward his teacher and his teacher's family are acknowledged as well as his obligation to pass on the teachings of medicine. Second, there is a list of rules the physician vows to follow in the practice of medicine.¹⁰⁹ In the list of rules, is the following: "Whatever houses I may visit, I will come for the benefit of the sick...." Taken at

¹⁰⁸Zuger and Miles, p. 1926.

¹⁰⁹Edelstein, Ludwig, Ancient Medicine: Selected Papers of Ludwig Edelstein, Temkin, Owsei and Temkin, C. Lilian, eds., Baltimore: Johns Hopkins Press, 1967.

face value, this may be considered a statement of purpose. The physician is, comes, exists for the benefit of the sick. It does not say, however, that the physician must take care of all sick, nor does it say that he must visit all houses. It says that the ones he visits, he will do so for the benefit of the sick, not to do other things which are spelled out in the rest of that sentence. Kass interprets this passage to be a reference to the physician in relation to the private life of the sick person; the physician comes "...this time not to define fitting therapeutic means but to delimit proper interpersonal conduct.... The doctor enters the intimate life-world of the patient and must act accordingly."¹¹⁰

The Hippocratic Oath is a part of the larger Hippocratic Corpus wherein clearer statements of purpose of the physician may be found. May states that, "In general terms, the art of healing attempted 'to do away with the sufferings of the sick, to lessen the violence of their diseases, and to refuse to treat those who are overmastered by their diseases, realizing that in such cases medicine is powerless.' (Hippocratic Corpus, L, VI, 4-6)."¹¹¹ This last point is important. According to Edelstein, the Hippocratic physician would naturally not hesitate to treat a patient who was not seriously ill, but if the disease was

¹¹⁰ Kass, Leon R., Toward a More Natural Science: Biology and Human Affairs, New York: The Free Press, 1985. p. 237.

¹¹¹ May, William F., The Physician's Covenant: Images of the Healer in Medical Ethics, Philadelphia: The Westminster Press, 1983. p. 92.

serious, there were reasons for not taking the case. One reason may be in the interest of the patient. Intervention when the patient was critically ill might be harmful or might be considered harassment. Another reason was in the interest of the physician whose reputation would suffer with a bad outcome.¹¹² Therefore, there is precedent in the Hippocratic Corpus for refusing to care for seriously ill patients.

There may be danger in interpreting the Hippocratic Oath too literally or in looking too hard at it for a literal pronouncement on the obligations of physicians. Edelstein says, "The Oath as a whole is hardly an obligation enforced upon the physician by any authority but rather one which he accepted of his own free will. It is not a legal engagement; as the wording indicates, it is a solemn promise given and vouchsafed only by the conscience of him who swears."¹¹³ Perhaps its value lies not in its literal meaning, but in the meaning that the swearer ascribes. One physician wrote in a letter to a journal, "As public awareness of acquired immunodeficiency syndrome (AIDS) reaches higher levels, we as physicians are being called on through increasing numbers of articles and editorials to stand bravely in the face of this disease and to uphold our oath to

¹¹²Edelstein, pp.96-8.

¹¹³Edelstein, p. 61.

treat patients regardless of personal risk."¹¹⁴ Perhaps it is enough that people think that the Oath includes this promise. Nevertheless, the obligation for which we search of physicians to care for patients with AIDS cannot be grounded in a literal interpretation of the Hippocratic Oath.

Thus, examination of the law, professional codes and principles, and complex medical tradition fails to establish an incontrovertible ethical obligation on the part of physicians to care for patients with AIDS. Instead, the rich tapestry of the tradition of the practice of medicine woven as it is with threads of self-sacrifice and personal commitment as well as individualism and self-protection presents a mixed picture of contradiction and ambiguity. In a continued search for that obligation, I shall now turn to modern ethical models of medical care.

¹¹⁴Clark, John B. Jr., "The Physician's Ethical Obligation to Take Care of Patients in Times of Plague," (Letter) Journal of the American Medical Association, March 4, 1988, 259:1325.

Chapter 4: Modern Ethical Models of Medical Care

My sister and mother have not been told. As long as I'm able to exist in society and go to work and keep my house I don't want to worry about involving them. Eventually it will come to a point Mom and Sis will have to know because I'm not going to be able to take care of myself. I think when I get out of here is when I have to dramatically start thinking about which direction I'm going in. I'll have to make dramatic changes--meaning selling my house, leaving my job. I could ask my mom if I could live with her, but then I'll have to let her know.

I take precautions. I don't want to think I can do anything I want. I don't want to cause anyone else to have it. So I try to avoid the lady in my life. She's very clean and she doesn't know. I don't want to destroy her life. One day I may get the courage up to tell her. She's a very nice girl and I don't want to hurt her. That's the really hard part about this. Right now I think it's better not to even have a relationship.

The Contract Model

There are many modern ethical models of medical care. This discussion will be limited to a few that exemplify current thinking. The one most commonly accepted both socially and legally has already been mentioned, the contract model. This model holds that the physician-patient relationship rests on a contract between the two parties. This contract has legal force in that once it has been established, the physician may not terminate the relationship without giving the patient sufficient time to find appropriate alternative care without being subject to liability for abandonment. The duty not to abandon a patient has roots both in common law and in professional principles of ethics. The physician-patient relationship, and therefore the contract, is established once the physician agrees to examine or treat the patient. In one case, the court held that the

relationship began when the physician accepted an appointment over the telephone with the patient who had specified the nature of her condition.¹¹⁵

It is clear from this model that the physician-patient relationship begins with the acceptance of the patient by the physician. There is nothing here that suggests that a physician must accept a particular patient or even a class of patients. Certainly, within this model there is room for a physician to say, "I shall not accept patients with AIDS."

This notion of relationship based on contractual agreement is consistent with the current AMA Principles of Medical Ethics, Section VI: "A physician shall, in the provision of appropriate patient care, except in emergencies, be free to choose whom to serve, with whom to associate, and the environment in which to provide medical services."¹¹⁶ It is also consistent with the view of medicine as a commercial enterprise where parties contract for goods or services as equal partners in a deal. The rights and duties of the parties involved derive from the contract. The contractor, the physician, is obligated to provide services consistent with his or her area of medical expertise and the ethical principles of his or her profession. The contractee, the patient, has the right to withdraw from the contract at any time if he or she feels that the terms of the contract have not been

¹¹⁵Annas, Hastings Center Report, p. 27.

¹¹⁶AMA "Principles...", 1980.

upheld (whatever they may be, for in most physician-patient relationships explicit terms are rarely spelled out and are subject to continuing and unexpected change with the changing condition of the patient) or, in an extreme case, he or she has the right to sue.

There are some positive points to this model.

The notion of the physician as contractor has obvious appeal. First, it breaks with more authoritarian models (such as parent or priest). It emphasizes informed consent rather than blind trust; it encourages respect for the dignity of the patient, who does not, because of illness forfeit autonomy as a human being; it also encourages specifying rights, duties, conditions, and qualifications that limit the contract. In effect, it establishes some symmetry and mutuality in the relationship between doctor and patient as they exchange information and reach an agreement, tacit or explicit, to exchange goods (money or services).¹¹⁷

On the other hand, there are problems with contractual medicine. Kass objects to attempts to define medicine as a trade rather than as a profession. He points to the inequality inherent in the "asymmetric" physician-patient relationship where the patient is more dependent on the physician even if the patient is not sick when seeking the services of the physician.¹¹⁸ However, when the patient is sick, certainly he or she is not capable of entering fully and knowingly into a contract of equals. As Cassell points out, "When we are ill, we not only become disconnected from our world and lose our sense of

¹¹⁷May, p. 117.

¹¹⁸Kass, p. 213.

omnipotence but reason fails us."¹¹⁹

Masters, as well, takes issue with formulating medical ethics on the notion of relationship based on contract. He lists the many ways in which a contract for medical services must differ from buying a car or a television set, for example. He concludes, "...to assert that the ethical obligations involved derive only from those contracts is misleading, especially since the information of the parties, their interests in the transaction, and their abilities to correct mistakes are so unequal."¹²⁰ The law, however, recognizes a difference between a commercial contract and a physician-patient contract or lawyer-client contract. These latter have been subject to fiduciary responsibilities where "...the normal rules of buyer and seller do not apply."¹²¹ In a fiduciary relationship, one party needing help or expertise seeks it from another party who, by virtue of his or her expertise or position to help, is held to be trustworthy and "...is bound to act in good faith and with due regard to the interests..." of the party seeking help.¹²²

¹¹⁹Cassell, Eric J., The Healer's Art, Cambridge, Massachusetts: The MIT Press, 1985. P. 35.

¹²⁰Masters, Roger D., "Is Contract an Adequate Basis for Medical Ethics?" The Hastings Center Report, December 1975, 5:24-28. P. 26.

¹²¹Holder, Angela Roddey, Medical Malpractice Law, 2nd Edition, New York: John Wiley and Sons, 1978. p. 225.

¹²²Holder, Angela R., "Do Researchers and Subjects Have a Fiduciary Relationship?" IRB: A Review of Human Subjects Research, January 1982, 6-7. p.6.

Nevertheless, the contract model creates a cold image of two strangers coming together but keeping their distance. In their detachment they agree on what each owes the other. There is no sense of emotion or involvement in human fears, aspiration, pain, suffering, delight, modesty or any of the other feelings that in reality pass between physician and patient unless these, too, are calculated and contracted for. There is no coming to know the other with decisions flowing from that knowledge. This model is an example of what Ladd calls legalism, "...the ethical attitude that holds moral conduct to be a matter of rule following, and moral relationships to consist of duties and rights determined by rules."¹²³

Patients and physicians have certain rights and corresponding duties, however, there is no duty to care for patients with AIDS unless it is explicitly spelled out in a contract such as the sort previously mentioned between a physician and a particular hospital or HMO. Then a patient with AIDS at that institution has the right to expect to be treated.

The Covenant Model

According to May, the contract model falls short in not allowing for anticipation of the individual nuances, contingencies and changes of focus inevitably a part of the physician-patient relationship, therefore the contract is

¹²³Ladd, John, "Legalism and Medical Ethics," The Journal of Medicine and Philosophy, March 1979, 4:70-80. P. 71.

external to the parties involved. May proposes a different model that is internal to the parties involved, that of the covenant modeled on the promises to God as revealed in the Scriptures. "Covenants cut deeper into personal identity."¹²⁴ The act of entering into a covenant alters the very being of the one who promises. "Initiation into a profession means, in effect, that the physician is a healer when healing and when sleeping, when practicing and when malpracticing."¹²⁵ This model also assumes protection for the more disadvantaged participants when there is an imbalance of power in the relationship.

As opposed to a marketplace contractual ethic, the biblical notion of covenant obliges the more powerful to accept some responsibility for the more vulnerable and powerless of the two partners. It does not permit a free rein to self-interest, subject only to the capacity of the weaker partner to protect himself or herself through knowledge, shrewdness, and purchasing power.¹²⁶

From the covenantal bond one may even fashion an obligation to treat. The physician's need for patients is acknowledged. In fact, "...a reciprocity of giving and receiving nourishes the professional relationship."¹²⁷ Thus, becoming a physician entails recognition of the paramount importance of the patient in what it means to be physician. The beginning physician owes a debt to the patient who allows himself or herself to be learned on, a

¹²⁴ May, p. 119.

¹²⁵ May, p. 119.

¹²⁶ May, p. 124.

¹²⁷ May, p. 115.

debt that gets paid in service to future patients.

A strength of the covenant model is that it calls for a commitment to treat not based on any individually established relationship. In other words, the physician-patient relationship is not just a result of who walks in the door and is accepted by the physician. The commitment to treat is a priori because it is not made just to the individual patient but to all patients, to the profession and to God.

The major problem with the covenant model is that its ontological effects derive from a religious construct. Motivation to behave well comes from belief in a higher, spiritual good.

A steadfast commitment to the needy and their cause requires more than an appeal to an ideal of rational self-interest abstracted from the world that we know. It requires placing that harsh world in the context of yet another world, more powerful, plausible, and gripping, that both deals with the sting of suffering and death and makes it possible, tolerable, imperative, and inviting for us to deal with the needy (and our own needs) in a better way.¹²⁸

It is a motivation that many physicians can find easy to reject, and one that does not meet the more universal needs of a medical ethic.

The Virtue-Based Model

In an attempt to capture a more acceptable motivation for behaving well, Masters and Zuger and Miles have proposed a virtue-based medical ethic. Masters bases this model on

¹²⁸ May, p. 126.

classical political philosophy where "...we find an ethics based on considerations of the 'common good,' 'virtue,' and the 'rule of law'--that is, principles fully consistent with the values of a civilized society generally held in the West."¹²⁹ Zuger and Miles refer to Scribonius Largus, a first century AD Roman physician who wrote that to belong to a profession means that one is committed to a certain end and has accepted an obligation to perform duties in order to achieve that end. For medicine, the end is healing and the duties involve treating the sick people requiring care.

"In its simplest sense, an ethic of virtue requires a virtuous moral agent whose character can be nurtured and trained and who can be held morally accountable for his actions."¹³⁰ Once a physician voluntarily chooses to join the medical profession, he or she accepts both that the end of medicine is healing and that to reach that end he or she must treat sick patients. The commitment, therefore, is over and above and independent of any commitment that follows to individual patients. A virtuous physician will then act in accord with this commitment or risk being held accountable by the profession for its violation.

What are the virtues demanded of a good physician? That may be a matter leading to some differences of opinion, however, once identified, they would become integral to the practice of

¹²⁹Masters, p. 27.

¹³⁰Zuger and Miles, p. 1927.

medicine. Assuming personal risk while treating patients with contagious disease would certainly require virtuous behavior. Zuger and Miles believe that the degree of risk posed by treating patients with AIDS would not call for virtues on the order of heroism, self-sacrifice or daring, but for courage and intellectual integrity. In speaking about Benjamin Rush who stayed to care for people when other physicians fled during the yellow fever epidemic in Philadelphia in 1793, Arras states, "His acts were courageous, not because they went beyond the call of duty, but rather because he did his duty when others might be sorely tempted to flee from it."¹³¹ Dr. Rieux in The Plague by Camus who stays to care for the people in the plague-ridden city would thus be considered a virtuous physician when he says,

"...there's one thing I must tell you: there's no question of heroism in all this. It's a matter of common decency. That's an idea which may make some people smile, but the only means of fighting a plague is--common decency."

"What do you mean by 'common decency'?" Rambert's tone was grave.

"I don't know what it means for other people. But in my case I know that it consists in doing my job."¹³²

Medicine as a Practice

Understanding the motivation for a physician to behave virtuously is a little more problematic. In other words, how do we answer the question, what's in it for me? It can be done by

¹³¹ Arras, p. 14.

¹³² Camus, Albert, The Plague, New York: Vintage Books, 1972. p.154.

digressing slightly and delving more deeply into medicine as a practice in the sense intended by MacIntyre who defines a practice as a "...coherent and complex form of socially established cooperative human activity through which goods internal to that form of activity are realized in the course of trying to achieve those standards of excellence which are appropriate to, and partially definitive of, that form of activity...."¹³³ While a practice requires knowledge and exercise of technical skills, it is not just a collection of those technical skills. The technical skills are put to use in achieving internal goods which are central to and partially definitive of the practice. Another crucial element to a practice is its history, so that "To enter into a practice is to enter into a relationship not only with its contemporary practitioners, but also with those who have preceded us in the practice...."¹³⁴ Thus, a practice has an on-going story that is informed by the stories of its practitioners; it is a story of stories. To use the metaphor we began with, a practice is a rich unfinished tapestry created and added to by threads woven by the individual practitioners. This last point is an important one to which we shall return.

¹³³MacIntyre, Alasdair, After Virtue: A Study in Moral Theory, Notre Dame, Indiana: University of Notre Dame Press, 1984. p. 187.

¹³⁴MacIntyre, p. 194.

To understand the difference between internal and external goods, MacIntyre gives an example of a child learning how to play chess. Playing chess, according to MacIntyre, is a practice. At first the child is not really interested in learning to play the game but is motivated to play and ultimately to win by the fifty cents that she will earn upon doing so. In order to win, the child will even cheat. Eventually, however, the child realizes that there is pleasure derived out of not just winning for the money, but from "those goods specific to chess...the achievement of a certain highly particular analytical skill, strategic imagination and competitive intensity."¹³⁵ MacIntyre points out that goods external to the practice, for example, money, status, fame, may all be achieved in other ways, however, those goods internal to the practice can only be achieved through participation in that practice. In fact, the goods internal to a practice can only be achieved through virtuous participation. If the child continues to cheat, she will never come to know the glory of winning through analytical skill and strategic imagination, nor will she appreciate a relationship between herself and her partner built purely on honest encounter.

External goods, when achieved, become someone's property. There is a finite amount of them, therefore, when one person achieves a quantity, there is less for other persons. As a result, there is competition for external goods with resultant

¹³⁵ MacIntyre, p. 188.

winner and loser. With internal goods there is competition to excel, however, a major difference is that achievement of internal goods, while limited to practitioners, is a good for the whole community participating in the practice. So that, for example, a painter creating a masterpiece or a musician composing a brilliant symphony contributes to the advancement of art and music and enriches all of the relevant community.¹³⁶

The plague doctors who were paid with money, housing and promises of citizenship are examples of physicians who were primarily motivated by external goods. However, once involved meaningfully in their labors, they may have acted courageously, and they may have also come to realize internal goods. The motivation for behaving virtuously, therefore, is achievement of goods internal to a practice, and a virtue is the "power" through which one realizes those goods.

What are the goods internal to the practice of medicine and what are the virtues necessary to achieve them? MacIntyre identifies three virtues necessary to any practice. They are justice, courage and honesty. Justice requires that we treat others uniformly and impartially. Courage is the capacity to risk harm or danger in exercising care or concern for individuals or communities. Honesty requires that we speak the truth. Without these, the achievement of excellence and of internal goods is impossible. Ladd points out some virtues necessary to

¹³⁶ MacIntyre, pp. 190-91.

the practice of medicine, "...it seems obvious that it is both possible and desirable to have doctors who are kind, compassionate, generous, courageous and wise in their capacity as doctors. Virtues like these are elements of what it means to be a good doctor."¹³⁷ Still, there may be other virtues essential to achievement of the as yet unidentified goods internal to the practice of medicine.

Achievement of goods is not all that is involved when one participates in a practice. Practice, as MacIntyre envisions it, also involves standards of excellence and obedience to rules. "To enter into a practice is to accept the authority of those standards and the inadequacy of my own performance as judged by them. It is to subject my own attitudes, choices, preferences and tastes to the standards which currently and partially define the practice."¹³⁸ The rich history and traditions of a practice contribute to these standards and partially define the practice. At the same time, however, the history and traditions reflect the continued participation and debate of the practitioners. In this way, the tapestry is never finished.

As we have already discovered, the standards of the practice of medicine even as they are informed by its history and traditions are what we are questioning. In terms of an

¹³⁷Ladd, John, "The Good Doctor and the Medical Care of Children," in Children and Health Care: Moral and Social Issues, Loretta M. Kopelman and John C. Moskop, eds., Dordrecht: Kluwer Academic Publishers, 1989.

¹³⁸MacIntyre, p. 190.

obligation to care for patients with AIDS, so far the practice of medicine has not been wholly satisfying. That is not to say that this standard for which we search does not exist within the practice of medicine, for I believe that it does, and we have seen tiny glimpses of it in Chapter 3. Finding its threads may be contingent on identifying certain goods internal to the practice of medicine and the virtue or virtues required to achieve them. It may require that we examine the problem in a different way.

Practice vs. Institution

Before turning to a different medical ethic, it would be worthwhile to look at the distinction that MacIntyre draws between practices and institutions. While medicine is a practice, a hospital or an HMO is an institution. The difference between the two is that an institution is "characteristically and necessarily" concerned with external goods. A hospital must put its energy into billing, collecting payments, buying equipment and personpower, paying salaries, giving promotions, recognizing and rewarding achievements. Its very structure relies on the acquisition and distribution of money, power and status. But the hospital as an institution is also enmeshed with the practice of medicine. The hospital, in fact, works to sustain the practice of medicine which could not survive without this sustenance.

Indeed so intimate is the relationship of practices to institutions--and consequently of the goods external to the goods internal to the practices in question--that institutions and practices characteristically form a single

causal order in which the ideals and the creativity of the practice are always vulnerable to the acquisitiveness of the institution, in which the cooperative care for common goods of the practice is always vulnerable to the competitiveness of the institution.¹³⁹

It is easy to see the corrupting influence of the institution of the hospital on the practice of medicine. In the beginning of Chapter 3, we noted that there is a "marketing mentality" arising in medicine that blurs the distinction between institution and practice to the point that we speak of the institution of medicine. Emanuel differentiates between the objective of the commercial enterprise, the pursuit of wealth, and the objective of the medical profession, devotion to a moral ideal. Yet, as we have seen, preservation of the free enterprise ideal of free choice of whom to serve seems staunchly to take precedence over any moral ideal of healing the sick. Conceptualization of the physician-patient relationship as one based on contract strengthens this image. Freedman makes this point clearly when he states, "Legally, as independent contractors, physicians are accustomed to being free of any obligation to attend to patients."¹⁴⁰ The strong forces of the institution so dominate the moral ideal of practice that sometimes they allow only a glimpse of the latter and sometimes not even that. Furthermore, as the major environment for the education of medical students and beginning physicians, the

¹³⁹ MacIntyre, p. 194.

¹⁴⁰ Freedman, p. 23.

hospital places emphasis on external rewards that is often in conflict with achievement of internal rewards of the practice of medicine. It is in the hospital that new physicians are socialized into the way of institutions rather than the way of practices.

Chapter 5: The Practice of Medicine

I've been using drugs 15 years. I started hanging around with the wrong people. I was about 16. I had this one person who was close. Everywhere you'd go you'd see us two together. I found out he was using. He said, "Hey, man, you wanna get high?" Finally, I said yes. I wanted to be like him and he wanted to be like me. Anything we did we did together. I said since he did it, I'll do it.

I've lived there six years so I have friends. I can make a friend of anybody. I don't think they know I'm ill. I'd just as soon as not--they would just ask questions.

It's hard to relate to my own brothers and sisters about this. I haven't told them. I feel it's a problem I've created, I've brought on myself. I don't want to bring heavy burdens on my family. They don't know.

Do physicians have an ethical obligation to care for patients with AIDS? It is now clear that this question cannot be addressed in terms of rights and duties. Legalism is not the answer. There are no laws to demand, there are no universal rules to instruct, there is no obvious requirement based on tradition to invoke with consequent entitlement. While the tradition of the practice of medicine offers glimpses of the threads of obligation, they must be pulled together to create an unmistakable pattern. If that strong nagging sense, that feeling, that physicians ought to care for patients with AIDS has validity, that validity must come from a heretofore unexplored source so fundamental to the practice of medicine that it cannot be denied. From where does that ought come? To locate that fundamental source, we need to know more about the practice of medicine. One way of doing so is to examine what some

contemporary writers on medical ethics have to say about the purpose of the practice of medicine and how it is achieved.

The Purpose of the Practice of Medicine

Kass states, "I trust it will shock no one if I say that I am rather inclined to the old-fashioned view that health--or if you prefer, the healthy human being--is the end of the physician's art."¹⁴¹ Kass is quick to point out that there is a difference between healthy and alive. He is not suggesting that the purpose of medical practice is always to keep patients alive. Next to the goal of health, he places the goal of relief of suffering and comfort. He equates healthiness with its etymological root definition wholeness. To make healthy is to make whole, to maintain health is to maintain wholeness. Human beings, according to Kass, must be understood teleologically as wholes. The adult human emerges complete as a whole after a period of development whose parts and systems function biologically in concert as one organism. An assault to one part of the person is an assault to the whole person. A state of health is a particular organism's natural norm. A return to health, therefore, is a return to "the well-working of the organism as a whole... an activity of the living body in accordance with its specific excellences."¹⁴² A return to health

¹⁴¹Kass, p. 159.

¹⁴²Kass, p. 174.

must also involve attention to the soul and/or psyche. However, in a situation when there is no longer the possibility of returning a patient to a "well-working" whole, "...when reasonable hope of recovery is gone, [the physician] acts rather to comfort the patient and to keep him company, as a friend and not especially or uniquely as a physician."¹⁴³

Kass differentiates this proper goal of medicine from "false goals" improperly assigned to the practice of medicine, for example, the patient's happiness and/or social adjustment. Pursuit of "scientific truth" is a true goal only insofar as it contributes to the art of healing; it is not an end in itself for the physician engaging in the practice of medicine. "Health and only health is the doctor's proper business...."¹⁴⁴

For Kass, the purpose of the practice of medicine is, to the extent possible, to maintain or restore the state of health, of wholeness. However, this is not an activity that can be accomplished by the physician alone. It requires a relationship

¹⁴³Kass, p. 163. I do not believe that Kass means to imply here that a dying patient may be abandoned by the physician to be cared for by a friend, or that any friend may take the place of the physician when there is no longer reasonable hope of recovery. On the contrary, the physician continues in relationship to the patient but the changed circumstances may create a requirement not for backing away, but for a new closeness, one that involves the sharing of a personal intimacy, one's death. The physician still comforts and relieves suffering as physician. The physician-patient relationship is not a static one; it is just that, a relationship, wherein one "relates", responds to changing needs. By friend, here, I believe, Kass means soul-mate, the kind of "other" one dying would want near.

¹⁴⁴Kass, p. 177.

between physician and patient. Kass asks the question: Whom does the doctor serve? He answers, "He [sic] serves his patients: the ill, the diseased, the dying, and also the worried-well who might be ill, diseased, or dying."¹⁴⁵

Admittedly, Kass is not totally happy with the word "serve" to describe what goes on between physician and patient because it implies mastery or lordship and the physician is neither master nor servant. While he is unable to find just the right all-inclusive word to say what he wants, suffice it to say that the point he makes is that the goal of the practice of medicine can only be fulfilled in relation to another, the patient.

Cassell chooses different language to arrive at basically the same point. He begins by differentiating among the terms "disease", "illness" and "sickness". Disease is something that affects an organ or a system, illness is what the person experiences. A person with kidney disease may have hypertension, hematuria or dysuria, but the having of the disease may also bring on pain, anxiety, sleep disturbances, disruption of activities, depression. The person, therefore, is suffering with an illness of which one part is the disease. As the illness deepens, the patient enters a state of sickness.

Disease begins the assault that threatens the person's "wholeness", of which Kass speaks. Cassell puts it another way. A person's health or wholeness is characterized by connectedness,

¹⁴⁵Kass, p. 191.

and the degree of his or her sickness is measured by the extent of diminution and loss of connection.

In health we know we are alive by our connectedness to the world. When we are totally disconnected we are dead. We are connected to the world by numerous physical phenomena--touch, sight, balance, smell, taste, hearing--and also by our interest in things and in others, by our feelings for people, by what we do and how necessary we are, by our place in the social scheme. To the degree that we feel real confidence in those connections, small details are unimportant and losing some connections is not so frightening as losing others. In illness, however slight, some of these contacts are lost....

As illness deepens, connections are increasingly cut off by the symptoms of sickness and by the forced withdrawal from society caused by sickness.¹⁴⁶

Furthermore, this loss of connectedness both brings about and is enhanced by loss of a sense of personal omnipotence and failure of reason, and loss of control over one's existence.¹⁴⁷

This loss of connectedness is beautifully revealed by Simenon in his novel, The Bells of Bicêtre, about a successful French newspaper publisher named Maugras who suffers a stroke and ends up in the hospital hemiplegic and temporarily aphasic. The story unfolds through the thoughts and feelings of Maugras as he faces a new existence cut off from who he was and what previously defined him. He begins to believe that "There was a conspiratorial world about him to which they all belonged.... As for him, he lay inert in his bed, at the mercy of people who compared notes about him, discussed his case, and passed

¹⁴⁶ Cassell, p. 27.

¹⁴⁷ Cassell, p. 45.

judgement on him."¹⁴⁸ As he loses touch with his old world and his old self, Maugras becomes fixated on the goings and comings, the smells, sights and sounds of his new hospital world. He becomes dependent on the regularity of the new routines and on the aid of new people. He finds even his thoughts altered by the experience of illness, "Thus a very ordinary starting point was enough to set going a train of thoughts which in normal life would have seemed absurd to him. Everything depends on one's point of view."¹⁴⁹

The importance of differentiating between disease and illness becomes clear in understanding Cassell's view of the goal and purpose of the practice of medicine. The physician is the healer who, in relationship with the patient, maintains or restores connection, or to use Kass's terms, maintains or restores wholeness. To do so the physician must know the patient well to know the manifestations of illness for that patient. The restoration of connection comes about through connection of physician and patient. This is not an impassioned and impersonal curing of disease. "Science does not serve patients in some unembodied manner; it does so through their doctors--in the relationship between patient and doctor."¹⁵⁰

Cassell, like Kass, has difficulty finding the all-inclusive

¹⁴⁸ Simenon, Georges, The Bells of Bicêtre, New York: Harcourt, Brace and World, Inc., 1963. p. 58.

¹⁴⁹ Simenon, p. 96.

¹⁵⁰ Cassell, p. 83.

right words to characterize the physician-patient relationship. Both men agree on the moral aspect of the relationship. Kass states, "I conclude that medicine necessarily remains a unique and intrinsically moral profession, with its own special norms and duties flowing from...the mutually shared self-consciousness of the doctor-patient relationship...."¹⁵¹ Cassell finds,

The relationship is founded on moral, not legal, terms. In moral terms the doctor is bound to the sick person. In such terms he [sic] can be seen as the subject as well as the master. It is the nature of that bond that is difficult to put into words. It has technical, personal, emotional, social, and ethical aspects, and the boundaries of each category are fuzzy and overlap the others.¹⁵²

Pellegrino concurs with Cassell's characterization of illness which he terms an "ontological assault" resulting in the patient's loss of freedom to make rational choices.¹⁵³ In this state of "wounded humanity" comparable to Cassell's concept of sickness, unable to deal with his or her vulnerability, the patient seeks the help of a physician. Having "professed" that he or she has special knowledge and skills to be used to heal and help the patient, the physician meets the patient in need and the relationship is established. The purpose of the practice of medicine once again is "...a right and good healing action...,"¹⁵⁴

¹⁵¹Kass, p. 213.

¹⁵²Cassell, p. 194.

¹⁵³Pellegrino, Edmund D., "Toward a Reconstruction of Medical Morality: The Primacy of the Act of Profession and the Fact of Illness," The Journal of Medicine and Philosophy, March 1979, 4:32-56. p. 52.

¹⁵⁴Pellegrino, p. 47.

and its forum is human relationship.

Thus, for all three of these men, the purpose of the practice of medicine is a complex activity called healing accomplished in and through relationship with another, the patient. The elements that each assigns to the activity of healing may be different and the language that each uses to describe it certainly is different. Both Kass and Cassell, as well as May, emphasize that one element of being a physician, in fact, of healing, is being a teacher both consciously and unconsciously, of facts regarding health promotion and maintenance and of feelings of caring and well-being. Ladd expands this point, "The doctor-patient relationship is itself, in many ways, often an educational relationship involving teaching as much as treating; sometimes, indeed, the teaching may be mutual."¹⁵⁵

Kass chooses language evocative of an image of healer/stranger who, having been sought voluntarily by one in need, is wholly knowing and understanding of the patient's vulnerability. The physician has special knowledge and, having "professed", has affirmed the moral nature of his activity.¹⁵⁶ While he carries out his duties with studied detachment, "...he must keep his private feelings to himself...", he is also aware that physician and patient share an "...equal relationship

¹⁵⁵Ladd, The Journal of Medicine and Philosophy, p. 79.

¹⁵⁶Kass, p. 215.

grounded in their mutual and equal participation in the ever-precarious, necessarily finite, yet daringly aspiring and hope-filled venture called human life."¹⁵⁷ Pellegrino's physician must have the capacity to "feel with" the patient, to experience something of the patient's anguish and anxiety and "existential situation".¹⁵⁸ Both of these men recognize specific obligations arising from the special nature of the physician-patient relationship, but Cassell comes closest to articulating that it is relationship qua relationship that empowers and motivates the physician.

For Cassell, being a physician is rooted in the very same connectedness so essential to the healing function, to the restoration of the patient's health. When he states, "In health we know we are alive by our connectedness to the world...by our feelings for people, by what we do and how necessary we are, by our place in the social scheme,"¹⁵⁹ he does not just mean patients. He says "we". Physicians, too, find themselves, express themselves, come alive in connection, in relationship, the very same relationship that is instrumental in achieving the goal of the practice of medicine. The physician is physician in relationship, with colleagues and students, but especially with patients; "...he can comfort and reassure in a manner so basic

¹⁵⁷Kass, p. 220.

¹⁵⁸Pellegrino, p. 52.

¹⁵⁹Cassell, p. 27.

that it is related to experiences in early infancy. His ability to make these connections with the patient does not stand apart from his other acts as a healer but is woven into the entire fabric of the healing function."¹⁶⁰ ¹⁶¹

¹⁶⁰ Cassell, p. 139.

¹⁶¹ There is a commonly accepted appeal to detachment in the practice of medicine that causes some confusion and leads to tentativeness in relationship and seeming contradiction. Physicians commonly advocate holding back, "not getting involved", keeping their emotional distance from patients purportedly as a method of self-protection from loss of objectivity and emotional burnout. Real concern for the self, however, would place the physician in relationship to his or her patients, relationship that may require objectivity at times but not unengagement. I hope to show that relationship provides an important context for objectivity, and that strength and personal growth, not emotional exhaustion are the true yield of the physician-patient relationship.

Mermann has found that physicians say, on the one hand, that establishing distance between self and patients may help alleviate job-related stress, while, on the other hand, the true gratification of being a physician comes from the extent of commitment to relationship. (Mermann, Alan, "Coping Strategies of Selected Physicians," in press.) It is far more likely that job-related stress is a function of demands placed on the physician by the institutions at which he or she practices and not by the practice of medicine. Under most circumstances there is not enough time, nor is encouragement given to take time, to fully appreciate relationship and the gratification that flows from it.

The pressures of the institution are often what require the physician to set certain priorities which can lead to the dissonance common to some physician-patient relationships as exemplified by that of Simenon's Maugras and his physician, Besson. Simenon says,

They were on different planes. This was a dialogue between deaf men, in so far as it could be called a dialogue. Besson was talking about tumors and arteriographs whereas Rene [Maugras], if he'd had a question to ask, if it had been possible to ask any man, even a friend, such a question, would have inquired: 'Are you satisfied with yourself?'" (Simenon, p. 64.)

It is a question appropriately asked of both the physician, Besson, impersonally speaking of tumors and arteriographs, and of the patient, Maugras, who in answering may provide the physician

Relationship

It is relationship then that is the central feature, the essence, of the practice of medicine. Only in relationship can the physician carry out his or her important purpose of healing. It is from relationship that we can expect to find the ought, the imperative for physicians to care for patients with AIDS. Rather than look to an ethic based on rights derivative obligations implying motivation from an authority outside the self whether it may be a rule or a law or a professional code, there must be an alternative ethic motivated from within the self. This motivation comes not from the self in relation to God as conceived in May's covenant, but from the self in relation to other people. Ladd, in rejecting legalism for this purpose, finds, "The moral duties that stem from interpersonal relationships can be brought together under the more general concept of responsibility....a concern that a person ought to have for another person's welfare by virtue of a special relationship that obtains between him and the other person."¹⁶²

with valuable information. It is a question Kemena asks himself. Kemena finds himself drawn to James, his patient with AIDS, "I wondered if he felt alone and rejected...." He wonders and cares, and yet believing it is inappropriate he steps back, "The last thing I wanted was to be drawn into his personal life." (Kemena, p. 21.) Kemena learns that it is only by allowing himself to know James that he grows as a person and as a physician. "I felt sorrow and loss. I also felt anger toward myself for all the opportunities I had had to help James but chose not to take....I do know that I miss James. In all my confused emotions, I am learning to temper my prejudices. Every person is special." (Kemena, p. 22.)

¹⁶² Ladd, The Journal of Medicine and Philosophy, p. 76.

This is not the potentially adversarial relationship between rights-holder and rights-owner as characterized by the contract model.¹⁶³ This is a giving and receiving relationship where both parties have something to gain each from the other. The doctor has special knowledge to use to help heal, but the patient has special knowledge too. The patient has knowledge of himself or herself without which the physician can only treat disease, not illness. Cassell puts it, "In the doctor patient relationship the sick person needs the doctor. The doctor also needs the sick person."¹⁶⁴ Nevertheless, there is an element of dependency in this relationship of the sort central to a teacher-student relationship which, as already noted, is also a large component of the physician-patient relationship. But, too, as Ladd points out, these sorts of relationships "...are dynamic--that is, they change and develop and their conditions change."¹⁶⁵ To put it in Cassell's language, to the extent connection can be restored, dependency, although never extinguished, may be diminished.

The centrality of relationship to the practice of medicine is special but not unique. Parenting and teaching, for example, are also defined in relationship. On the other hand, some other

¹⁶³As Ladd points out, the physician-patient relationship may turn into an adversarial relationship, but this is much more likely to be the case when the relationship is based on claims of rights and obligations to begin with.

¹⁶⁴Cassell, p. 194.

¹⁶⁵Ladd, The Journal of Medicine and Philosophy, p. 79.

practices especially those with a service component may consider relationship an element but it is not the essential feature. Take, for example, the practice of firefighting. The firefighter does not fulfill his or her goal in relationship. Certainly there must be cooperation with and dependency on other firefighters just as there must be among physicians, and certainly when faced with an air-starved child the firefighter relates intimately with that child and provides resuscitation and oxygen. There is an imperative to do so out of the nature of the practice, but the momentary intimacy, while it may occur, does not need to occur ever for the firefighter to be a firefighter. The firefighter can fulfill the goals of the practice with hose and hatchet and ladder and burning building.

Similarly, different specialties in the practice of medicine ground themselves to a greater or lesser degree in relationship. It is true that every specialty requires patients to exist, but the actual relationship may be peripheral to the practitioner's activities. For example, pathologists may fulfill their goals without knowing or entering into relationship with patients. The same may be true for certain radiologists. Some surgical specialties unfortunately may behave minimally in relationship. While surgeons greet the patient and impart certain information, the patient as person may take up very little time. In the operating room anesthesia and the elaborate dance of draping the patient exclude the patient's personality and leave the surgeon only a deep red hole with which to interact. Pediatrics,

internal medicine, family medicine, obstetrics and gynecology, these are the practices that are or ought to be wholly grounded in relationship, those subsequently referred to as "core" practices and about which more will be said in the next chapter.

Chapter 6: The "Core" Practice of Medicine

You shouldn't condemn a person because he's infected. It doesn't make him a bad person. It's the difference between knowing something in your head and in your heart--accepting it. I think it's a doctor's job too. You have to get to know your patients. That way a person can trust you more. That way if something happens he can turn to you because he can trust you. It's hard to get really close to one doctor because they'll be here two weeks and then they're gone and they'll assign you to someone else.

I enjoy the people here. I look at it as a hospital but it's also a place to relate to people. I get along with people. This is the heart I've got. As long as I've been on the street my heart has not turned cold. I can't turn my back on a person. I look at it, what goes around comes around. Some day you may be the one in need.

How do we find a requirement to care for patients with AIDS based on the central and fundamental importance of relationship to the practice of medicine? We can start by quoting Piaget, "...apart from our relations to other people, there can be no moral necessity."¹⁶⁶ Of course, that is not enough. We need to locate the motivation for behaving morally in the fact of relationship. In other words, the goods internal to the practice of medicine need to be seen as accruing from relationship in order for relationship to be motivational. It will help to define relationship according to the "self-other" relation as outlined by Whitbeck in her ontology.

¹⁶⁶ Piaget, Jean, The Moral Judgement of the Child, New York: The Free Press, 1965. p.196.

A Different Ontology¹⁶⁷

Whitbeck accepts MacIntyre's definition of a practice but develops her ontology around a certain sort of practice, what she considers the "core" practice, "that of the (mutual) realization of people."¹⁶⁸ Both teaching and healing are core practices. She proposes "...a self-other relation that is assumed to be a relation between beings who are in some respects analogous, and the scope and limits of that analogy...are something to be explored in each case."¹⁶⁹ This concept is different from more traditional ontologies based on an oppositional dualism wherein the other is defined as opposite to the self. Oppositional dualism, Whitbeck points out, is the basis for the ontological theories of many philosophers from Aristotle to Freud. In such an ontology, for example, altruism is defined by being the opposite of egoism, teacher is the opposite of student and physician is the opposite of patient. In an oppositional dualism, the self proves itself in a struggle to master the other. "A recurrent tendency that results from the opposition of self and other is to deny the existence of the other to a greater

¹⁶⁷ An ontology may be defined as a description of the state of "being" and of the conditions that surround "being".

¹⁶⁸ Whitbeck, Caroline, "A Different Reality: Feminist Ontology," Beyond Domination: New perspectives on Women and Philosophy, Carol Gould, ed., Totowa, N.J.: Rowman and Allanheld, 1983. p. 65.

¹⁶⁹ Whitbeck, p. 75.

or lesser degree or to make any existing other into the self."¹⁷⁰
 As an aside, it is noteworthy that this tendency is certainly exaggerated when the patient has a disease like AIDS which possesses polluting capacity in the sense discussed by Douglas.¹⁷¹

In Whitbeck's view the self and other may have different characteristics but they are not opposites. They also have many similar characteristics. In fact, it is more appropriate to speak of self-others since the relation is not fundamentally dyadic. The self is not defined in a succession of dualistic encounters, but in a more complex constant and ongoing exposure to enriching others.¹⁷² Since the self and others are analogous beings, they are also complimentary beings. She states,

Since the relations of the self to others are relations among analogous beings, and the scope and limits of that analogy are to be discovered or, if the other is a person, to be mutually created and transformed, relationships between people are understood as developing through identification and differentiation, through listening and speaking with each other, rather than through struggles to dominate or annihilate the other.¹⁷³

Since one is not defined in opposition to others, one is defined in relation to others. In this view, "...relationships to other people are fundamental to being a person, and one cannot become a

¹⁷⁰ Whitbeck, p. 75.

¹⁷¹ Douglas, p. 113. As noted in Chapter 2, Douglas defines a "polluting person" as someone who "...is always in the wrong. He has developed some wrong condition or simply crossed some line which should not have been crossed and this displacement unleashes danger for someone."

¹⁷² Whitbeck, p. 76.

¹⁷³ Whitbeck, p. 76.

person without relationships to other people."¹⁷⁴ The person is an historical being realized in and through relationship and practices and whose history is one of relationships. Therefore, past relationships as well as future relationships nurture and enhance and contribute to the completion of the person.

Self-Realization

Whitbeck's relationships are "lived relationships". She is careful to point out that the concept of relationship is different from the notion of a role which is not in and of the self but may be cast off if convenient, like "...something that a person can take on and later reject and be no more affected by than the clothing one has temporarily worn."¹⁷⁵ Whitbeck's ontology as applied to the physician is similar to May's claim that "...the physician is a healer when healing and when sleeping, when practicing and when malpracticing."¹⁷⁶ Furthermore, as stated earlier, physicians and patients need each other. In the context of Whitbeck's ontology, they need each other in order that they may be themselves. As May puts it, "No one can watch a physician nervously approach retirement without realizing how much the doctor has needed the patients to be

¹⁷⁴Whitbeck, p. 77.

¹⁷⁵Whitbeck, p. 77.

¹⁷⁶May, p. 119.

himself or herself."¹⁷⁷

This point is also echoed in Cassell's concept of connection, "Our place in society, group identity, and our loved ones allow us to define ourselves. Without them we are nothing."¹⁷⁸ Kass uses his own language to express this concept, in relationship with patients, the physician, "...has the opportunity, rarely given to other human beings, to see without illusion the darker side of the human condition, and to see humanity, unprotected and stripped of pretense, struggling gamely to preserve itself."¹⁷⁹ Simenon's Maugras also has this insight. "At this moment Maugras was not interested in his own health, but in other people. He felt the need to scratch beneath their surface, convinced that if he succeeded he would see more clearly into himself."¹⁸⁰ In other words, in relationship with patients, the physician has the opportunity to express, to come to know and to see himself or herself.

In summary, in the practice of medicine, the central, fundamental construct on which rests fulfillment of the goals of the practice is relationship. This relationship is central also to the self-realization of the physician/practitioner. Therefore, it is from relationship that spring goods internal to

¹⁷⁷ May, p. 116.

¹⁷⁸ Cassell, p. 77.

¹⁷⁹ Kass, p. 238.

¹⁸⁰ Simenon, p. 106.

the practice of medicine one of which can now be identified as self-realization.¹⁸¹

Responsibility

Whitbeck's ontology is the basis for an ethic that recognizes as the fundamental moral notion responsibility "...for (some aspect of) another's welfare arising from one's relationship to that person."¹⁸² This ethic differs from the rights view of ethics which holds that a moral right is the fundamental moral notion wherein

People are viewed as social and moral atoms, armed with rights and reason, and actually or potentially in competition and conflict with one another.... If any attention is given to relationships on the rights view, it is assumed they exist on a contractual or quasi-contractual basis and that the moral requirements arising from them are limited to rights and obligation.¹⁸³

On the contrary, an ethic of responsibility does not proffer a set mode of conduct in response to a stated claim, but calls for discretion on the part of the responsible agent.¹⁸⁴ It is the moral integrity of the responsible agent that is at stake in

¹⁸¹The identification of self-realization as an internal good of the practice of medicine will become more fully evident in Chapter 7 following the discussion of the ethical self.

¹⁸²Whitbeck, p. 82.

¹⁸³Whitbeck, p. 79.

¹⁸⁴For an excellent and comprehensive review of the ethics of responsibility and its relationship to decision making in the practice of medicine, see Powell, Patricia Mary, Deciding for Others: Rights and Responsibilities in Medical Ethics. M.D. Dissertation, Yale University, New Haven, Connecticut, 1987.

deciding to behave responsibly, a decision that arises from a position of relation, of care, of concern. In fact, Ladd states, "...being responsible is a kind of virtue, and being irresponsible is a kind of vice; for it is impossible to be a good parent, a good friend, a good doctor, or a good nurse without taking one's responsibilities for the other seriously, that is acting responsibly toward him, being responsible."¹⁸⁵

Thus, a heretofore unidentified virtue essential to achievement of self-realization, a good internal to the practice of medicine, is responsibility. The physician is physician in relationship to patients and only to the extent that he or she acts virtuously by claiming moral integrity in being morally responsible for and to those patients. Recall that a characteristic of internal goods is that their achievement is a good for the whole community participating in the practice. Since, as Whitbeck states,

... the fulfillment of the responsibilities for the welfare of others that attends one's relationships to them is essential to the maintenance of moral integrity, each person's moral integrity is integrally related to the maintenance of the moral integrity of others. Thus, on this view their self-interest is not something that can be neatly separated from the interests of others. ...all parties to the relationship and participants in the practice emerge and develop and therefore, the relationships and practices also develop. Furthermore, what counts as proper development is itself partially specified in terms of acquisition of the very virtues necessary to engage in the key practices of mutual realization.¹⁸⁶

¹⁸⁵Ladd, The Journal of Medicine and Philosophy, p. 76.

¹⁸⁶Whitbeck, p. 81.

Therefore, by entering into relationship with and being morally responsible to and for patients, physicians both fulfill themselves as physicians and further the good of the practice of medicine. But what about patients with AIDS? Must physicians enter into relationship with all patients including patients with AIDS in order to achieve self-realization, or may physicians achieve self-realization through the relationships that they choose to enter? The fundamental question continues to haunt us, and, as we have already learned, an answer will not come simply or easily.

Chapter 7: The Essence of the Practice of Medicine

Last time I was in the hospital I almost died. I was disappointed that I hadn't died. Then it would have been all over. My family wouldn't--right now they haven't gone through anything they'll have to go through. It would have been over. Now I have to look forward to it all ahead. It's going to be harder on them than on me. They've never seen it. I know what to expect. Seeing others--a friend of mine was diagnosed down in Jersey and three weeks later we were going to his funeral. My mother and my family have never seen anything like it. They know I'm going to have my good days and bad days, but they don't know that my bad days will outweigh the good ones.

From her research, Lyons has identified two distinct modes of describing the self in relation to others--separate/objective and connected. The separate/objective self relies on impartiality, objectiveness and detachment in relationships in order to be attentive to rules and maintain fairness. The connected self relies on interdependence, responsiveness and caring. Lyons states, "To be responsive requires seeing others in their own terms, entering into the situations of others in order to know them as the others do, that is, to try to understand how they see their situations."¹⁸⁷ The practice of medicine requires each of these approaches at various times.¹⁸⁸

¹⁸⁷Lyons, Nona Plessner, "Two Perspectives: On Self, Relationships, and Morality," Harvard Educational Review, May 1983, 53:125-145. p. 135. See, also, Gilligan and Powell.

¹⁸⁸Gilligan, Lyons and other developmental psychologists have identified two different images and ideas of making moral choices. Lyons states, "One view has come to dominate modern moral psychology--the image of the person in a discrete moment of individual choice." This view is of the "separate/objective" self relying on rules "to maintain fairness and reciprocity in relationships." The second view is of "the individual connected and attending to others," who relies on "the activity of care" to maintain and sustain caring and connection in relationships. (See Lyons, pp. 125-144.) As examples of these two different views,

Lyons offers the following answers given by two different research subjects to the question, "What does morality mean to you?":

1. Morality is basically having a reason for a way of knowing what's right, what one ought to do; and, when you are put into a situation where you have to choose from among alternatives, being able to recognize when there is an issue of "ought" at stake and when there is not; and then...having some reason for choosing among alternatives.

2. Morality is a type of consciousness, I guess, a sensitivity to humanity, that you can affect someone else's life. You can affect your own life, and you have the responsibility not to endanger other people's lives or to hurt other people. So morality is complex. Morality is realizing that there is a play between self and others and that you are going to have to take responsibility for both of them. It's sort of a consciousness of your influence over what's going on.

Thinking of the sort exemplified by answer number 1 has been traditionally attributed to men and thinking of the sort exemplified by number 2 has been traditionally attributed to women. (For an explanation of this assignment see Gilligan, Carol, In A Different Voice, Cambridge, Massachusetts: Harvard University Press, 1982.) Recent work by Gilligan, Lyons and others, however, shows that both men and women are fully capable of reasoning both ways. Lyons states, "This concern for connection to others should not be considered as present only at particular stages or as issues pertaining only to women. Although men and women tend to understand and define relationships in different ways, definition of self in relation to other is found in both sexes at all ages." (Lyons, pp. 141-2)

Several of the sources used for this paper are identified in their titles as "feminine" or "feminist". It is unfortunate in some respects that they are identified in this way. These sources contain arguments based on connection and care-based thinking, which is not and should not be limited to the moral consciousness of one sex and not the other. In fact, as I have shown, this thinking is predominant in the work of several male writers and has an on-going valid historical place in the story of the practice of medicine. Levine states, "Care oriented reasoning is most compatible with the attitudes and behaviors most of us value in the sorts of persons we wish to have serving as our personal doctors." (Levine, Robert J., "Medical Ethics and Personal Doctors: Conflicts Between What We Teach and What We Want," American Journal of Law and Medicine, 1987, 13:351-64. p. 364.) What is crucial to the practice of medicine is that physicians make appropriate use of both modes of reasoning. Deciding whether or not to treat sick patients calls for care and

As we have already found, the obligation to care for patients with AIDS cannot be located in rules and an appeal to legalistic fairness. It can, however, be located in a practice which has as its essence relationship based on responsibility and caring.

Caring

It is important to keep in mind that physicians need relationship for all of the reasons already discussed and that that relationship is a "caring" relationship; the physician cares for the patient and not only in the medical sense. To support this claim, merely think of how wrong it sounds to say that physicians do not or should not care for their patients. In order to act responsibly toward the patient, the physician must have regard for the patient and a desire to act for the patient's well-being. Theoretically an unengaged physician may treat a patient's disease, but to treat a patient's illness one must come to know and care for the patient as a person. In order to restore a patient to wholeness and connection, the physician must have some idea of what wholeness and connection mean for that patient. This idea comes about through caring. Caring, therefore, may be considered a virtue in the practice of medicine. This is not a novel idea. In 1927, Peabody, a highly regarded clinician and teacher, wrote, "...the secret of the care

connection-based reasoning for the reasons expressed in this paper. Other aspects of patient care may require a rule-based approach.

of the patient is in caring for the patient."¹⁸⁹

Caring is not the same thing as loving. Both involve engrossment in the one cared for, but the intensity and duration of engrossment varies. Loving is one type of caring. Noddings explains,

While I care for my children throughout our mutual lifetimes, I may care only momentarily for a stranger in need. The intensity varies. I care deeply for those in my inner circles and more lightly for those removed from my personal life.... The acts performed out of caring vary with both situational conditions and type of relationship.... At bottom, all caring involves engrossment. The engrossment need not be intense nor need it be pervasive in the life of the one-caring, but it must occur. This requirement does not force caring into the model of romantic love, as some critics fear, for our engrossment may be latent for long periods.¹⁹⁰

Noddings builds on Whitbeck's ontology and accepts relation as basic when she develops an ethic of caring. She uses the terms "one-caring", which for our purpose is the physician, and "cared-for", the patient. In caring, the one-caring "feels with" the cared-for. Recall Pellegrino's use of the same words. Noddings differentiates "feeling with" from empathy, a form of projection of one's personality onto another in order to attempt to understand his or her feelings or actions. Noddings states,

The notion of "feeling with" that I have outlined does not involve projection but reception. I have called it "engrossment." I do not "put myself in the other's shoes," so to speak, by analyzing his reality as objective data and

¹⁸⁹Peabody, Francis W., "The Care of the Patient," The Journal of the American Medical Association, March 19, 1927, 88:877-882. p. 882.

¹⁹⁰Noddings, Nel, Caring: A Feminine Approach to Ethics and Moral Education, Berkeley, California: University of California Press, 1984. pp. 16-17.

then asking, "How would I feel in such a situation?" On the contrary, I set aside my temptation to analyze and to plan. I do not project; I receive the other into myself, and I see and feel with the other.¹⁹¹

To the senses through which Noddings receives the other can be added touch since the physician also receives the patient through his or her hands and fingers.

The Story

The physician first receives the patient through the patient's story, his or her narrative. Brody states, "We are, in an important sense, the stories of our lives. How sickness affects us depends on how sickness alters those stories."¹⁹² The physician cannot know a patient until he or she hears the patient's story. Recall that Whitbeck says that relationships develop through listening and speaking with each other. Brody considers the physician's openness to story to be an ingredient of his or her compassion, or to use the language we started with, caring. In fact, in the giving and receiving of the patient's story begins the growth of the fullness of relationship which has the potential for the virtuous physician to culminate in self-realization. In speaking about a surgeon friend Brody says, he "...has been heard to remark that the major reward in being a physician is having the opportunity to sit in an office all day

¹⁹¹Noddings, p. 30.

¹⁹²"Brody, Howard, Stories of Sickness, New Haven, Connecticut: Yale University Press, 1987. p. 182.

while one patient after another comes in to tell him his or her life story in full, frank, and intimate detail."¹⁹³ Here is echo of Kass's recognition of the rare opportunity given to physicians to "see humanity". Here, too, is a reminder of Cassell's insight into connection. Physicians, too, have stories, stories that tell tales of relationship. Both patients' and physicians' stories, in fact, will be stories of relationship because that is what they, patients and physicians, are. These stories then are woven into the unfinished tapestry that is the story of the practice of medicine.

Although Noddings's description of receptivity seems to have a mystical quality, it is not mystical. It is descriptive of a common transformation that occurs by interlocking stories, by getting to know someone in a way that the knowledge causes one's ideas to change or be affected so that where before the person may have been a stranger or a superficial acquaintance, now the person is a cared-for. It is the transformation experienced by Kemena as he learned to care for James.

Noddings describes the transformation that takes place as she receives a teacher for whom previously she had little regard.

Somewhere in the light banter of lunch talk, he begins to talk about an experience in the wartime navy and the feelings he had under a particular treatment. He talks about how these feelings impelled him to become a teacher. His expressions are unusually lucid, defenseless. I am touched--not only by sentiment--but by something else. It is as though his eyes and mine have combined to look at the scene he describes. I know that I would have behaved differently in the situatuion, but this is in itself a

¹⁹³ Brody, p.3.

matter of indifference. I feel what he says he felt. I have been invaded by this other. Quite simply, I shall never again be completely without regard for him. ...I am now prepared to care whereas previously I was not.

The transformation that takes place through caring for a member of an outcast or stereotyped group can cause one to realize that there is a unique person behind the stereotype. That realization can make it impossible for one ever again to generalize with such confidence. This point may be illustrated by a personal experience.

In the early 1970s I taught a course on prejudice to junior high school students. Toward the end of the year I gave the students a quiz on stereotypical attitudes toward various racial, ethnic and religious groups that asked questions such as the following one: Do you believe that there is a group of people that tends to be cheap and tries to take advantage of people to gyp them out of their money? After asking a series of such questions, I asked the class as a group for a response, "How many people believe that there is a group of people that...?" In response to the above question, most of the students waived their hands. I asked, "Which group?" The students called out, "Jews." A discussion followed. Someone then called out something like, "But there's this man who is Jewish who lives down the street, and he's really nice. He makes dinner for me sometimes and I can really talk to him about things." After teaching at this school for four years and having gotten to know my students well and having them come to know and care for me, I quietly countered,

"I'm Jewish." In the profound silence that followed my revelation we just looked at each other. Then a small voice from the back of the room asserted, "But we know you and you're different." My students had discovered the secret of relationship, of caring. Out of receiving and seeing comes knowing in a way that makes group identity or appearance irrelevant. Insight is born of interlocking stories.

While Nodding's receptive mode is primarily affective, listening, looking, feeling, it is often accompanied by a lateral move into a mode of rational problem solving. Noddings says, "We quite properly enter a rational-objective mode as we try to decide exactly what we will do in behalf of the cared-for. If I am ill-informed, or if I make a mistake, or if I act impetuously, I may hurt rather than help the cared-for."¹⁹⁴ Clearly, both modes are required to act in the best interest of the patient. What is crucial is that the physician be capable of accessing both modes. "Hence, in caring, my rational powers are not diminished but they are enrolled in the service of my engrossment in the other."¹⁹⁵ A physician who cares will place a great deal of value on medical knowledge and skill. As stated earlier, technical skills are put to use in achieving the goods internal to a practice. However, there can be two sides to being ill-informed--one is the technical knowledge side, the other,

¹⁹⁴Noddings, p. 26.

¹⁹⁵Noddings, p. 36.

more often overlooked, is the knowledge of patient side.

Natural vs. Ethical Caring

To understand the ethic of caring, certain concepts must be understood. Noddings distinguishes natural caring, for example parent for child, friend for friend, lover for lover, from ethical caring. Ethical caring is the relation in which the other is met morally, and it is a reflection of natural caring, the relation in which caring is a response to love or natural inclination. Ethical caring occurs in the realm of Whitbeck's "lived relationships", "...not legal or biological relationships, although relationships in the latter sense may influence lived relationships."¹⁹⁶ Noddings states that natural caring is "...the human condition that we, consciously or unconsciously, perceive as 'good.'"¹⁹⁷ When we care ethically, we are attempting to emulate a state of natural caring toward which we "long and strive." "...it is our longing for caring--to be in that special relation--that provides the motivation for us to be moral. We want to be moral in order to remain in the caring relation and to enhance the ideal of ourselves as one-caring."¹⁹⁸ This last point clarifies the notion of Piaget as stated at the beginning of Chapter 6 that "...apart from our relations to other people,

¹⁹⁶ Whitbeck, p. 77.

¹⁹⁷ Noddings, p. 5.

¹⁹⁸ Noddings, p. 5.

there can be no moral necessity."¹⁹⁹

Noddings uses the image of concentric circles sending forth chains with ourselves at the center. Closest to us are our most intimate cared-for, those for whom we naturally care.

As we move outward in the circles, we encounter those for whom we have personal regard. Here, as in the more intimate circles, we are guided in what we do by at least three considerations: how we feel, what the other expects of us, and what the situational relationship requires of us. Persons in these circles do not, in the usual course of events, require from us what our families naturally demand, and the situations in which we find ourselves have, usually, their own rules of conduct.²⁰⁰

It is in these circles that physicians encounter their patients. Farther out still are others not yet encountered but linked to current patients by "chains of caring". Noddings says, "The construction of such formal chains places us in a state of readiness to care."²⁰¹

In other words, these farther out patients are the potentially cared-for. The physician is prepared to care for these patients; they share the same potential as those now cared-for. The same opportunity for the physician to be fulfilled as physician exists in relationship to these unknown others.²⁰² But what if the physician does not feel like caring

¹⁹⁹Piaget, p. 196.

²⁰⁰Noddings, p. 46.

²⁰¹Noddings, p. 17.

²⁰²There are many legitimate reasons for a physician to limit his or her practice. As pointed out earlier, no one expects an ophthalmologist, for example, to treat a patient's kidney disease, therefore, the practice of ophthalmology will be limited to patients with eye disease. It is expected, however, that an

for one or more of these yet-to-come-closer patients? Is this not the same question that we have been asking all along?

In Noddings's language, in questioning whether to care for these others, the physician is questioning the "I must", the moral imperative of ethical caring. "I may recognize the internal 'I must,' that natural imperative that arises as I receive the other...."²⁰³ When the "I must" is indistinguishable from the "I want" as it often is with natural caring, there is no difficult decision to make. But when there is a conflict as with caring for patients with AIDS, the physician may want to reject the "I must". Noddings states, "I may reject it instantaneously by shifting from 'I must do something' to 'something must be done,' and removing myself from the set of possible agents through whom the action should be accomplished."²⁰⁴ The statements discussed earlier put out by the AMA and other professional organizations regarding the physician's obligation to care for patients with AIDS allow physicians to reject the "I must" in this exact manner.

ophthalmologist who routinely examines the eyes of diabetic patients will also examine the eyes of a diabetic patient with AIDS. Certainly an ophthalmologist who finds fulfillment as a physician in caring for patients with diseases of the eye has the same opportunity for fulfillment caring for a patient with cytomegalovirus retinitis. Likewise, a general internist who fulfills himself or herself taking care of patients with problems of every organ system has the same opportunity for self-fulfillment taking care of patients with similar complaints but who also are HIV positive.

²⁰³Noddings, p. 47.

²⁰⁴Noddings, p. 81.

The Ethical Ideal and the Ethical Self

The answer for which we search may finally be had by examining the concepts of the ethical ideal and the ethical self. Noddings explains,

When I reflect on the way I am in genuine caring relationships and caring situations--the natural quality of my engrossment, the shift of my energies toward the other and his projects--I form a picture of myself. This picture is incomplete so long as I see myself only as the one-caring. But as I reflect also on the way I am as cared-for, I see clearly my own longing to be received, understood, and accepted. There are cases in which I am not received, and many in which I fail to receive the other, but a picture of goodness begins to form. I see that when I am as I need the other to be toward me, I am the way I want to be--that is, I am closest to goodness when I accept and affirm the internal "I must." Now it is certainly true that the "I must" can be rejected and, of course, it can grow quieter under the stress of living. I can talk myself out of the "I must," detach myself from feeling and try to think my way to an ethical life. But this is just what I must not do if I value my ethical self. (emphasis added)²⁰⁵

Like Noddings, MacIntyre considers striving toward the ethical ideal to be "a quest" for "a conception of the good."²⁰⁶ This picture of oneself "closest to goodness" in caring relationship, therefore, is the ethical ideal.

The ethical self is the physician the way the physician wants to be, the responsible, caring healer, the teacher, in Cassell's terms, the one bound to patients, the one that strives to come as close as possible to the ethical ideal. Lebacqz calls this picture of oneself as described by Noddings an "ideal image" which, she says, emerges and begins to take shape "...in the life

²⁰⁵ Noddings, p. 49.

²⁰⁶ MacIntyre, p. 219.

histories of exemplary professionals or role models."²⁰⁷ Both Lebacqz and MacIntyre tell us that men and women learn their parts, learn to be the characters they are in a practice through the hearing of stories, and from the stories of the heroes and heroines of a practice emerges this "ideal image", the role model for the ethical self.²⁰⁸ The potent ingredient of those stories, the shaper of the ethical ideal, is relationship. Recall Whitbeck's ontology and the view that "...relationships to other people are fundamental to being a person."²⁰⁹ Recall that the essence of the practice of medicine is relationship, that relationship is fundamental to being a physician. The ethical self is discovered in relationship and is dependent on relationship, and the story of the ethical physician is a story of relationship.

Noddings says, "The ethical self is an active relation between my actual self and a vision of my ideal self as one-caring and cared-for. It is born of the fundamental recognition of relatedness: that which connects me naturally to the other, reconnects me through the other to my self."²¹⁰ Hear again the words of Cassell, "...our very existence is defined by

²⁰⁷ Lebacqz, Karen, Professional Ethics: Power and Paradox, Nashville, Tennessee: Abingdon Press, 1985. p. 49.

²⁰⁸ See Lebacqz, p.49, and MacIntyre, p. 216.

²⁰⁹ Whitbeck, p. 77.

²¹⁰ Noddings, p. 49.

our relationships--our connection to life itself."²¹¹ In knowing and caring for the patient, the physician knows and cares for himself or herself as physician. Noddings states, "...caring for my ethical self commits me to struggle toward the other through clouds of doubt, aversion, and apathy."²¹²

Noddings's concept of the ethical self draws on Whitbeck's ontology. Whitbeck argues that, "...the person is a relational and historical being whose creativity and moral integrity are both developed and realized in and through relationships and practices."²¹³ Furthermore, because we are defined in relationship and "...because relationships past and present, realized and sought, are constitutive of the self,...the actions of a person reflect the more or less successful attempt to respond to the whole configuration of relationships."²¹⁴ Whitbeck's moral integrity and Noddings's ethical ideal are the offspring of relationship which may be nourished or starved depending on the responses of the self to others.

An Answer

Right here is the question we have been asking and an answer. Are physicians obliged to answer the "I must" and care

²¹¹ Cassell, p. 77.

²¹² Noddings, p. 50.

²¹³ Whitbeck, p. 66.

²¹⁴ Whitbeck, p. 76.

for patients with AIDS? Yes, resoundingly yes. Physicians reject the "I must" at great peril. Noddings states, "I feel the moral 'I must' when I recognize that my response will either enhance or diminish my ethical ideal. It will serve either to increase or decrease the likelihood of genuine caring. My response affects me as one-caring."²¹⁵ The individual physician's response affects him or her as caring, responsible physician; it affects the story he or she will have to tell; it affects his or her ability to achieve the internal goods of medicine including self-realization; and, therefore, it affects the practice of medicine. Noddings eloquently expresses the dimensions of the choice at hand:

We feel that we are, on the one hand, free to decide; we know, on the other hand, that we are irrevocably linked to intimate others. This linkage, this fundamental relatedness, is at the very heart of our being. Thus I am totally free to reject the impulse to care, but I enslave myself to a particularly unhappy task when I make this choice. As I chop away at the chains that bind me to loved others, asserting my freedom, I move into a wilderness of strangers and loneliness, leaving behind all who cared for me and even, perhaps my own self. I am not naturally alone. I am naturally in relation from which I derive nourishment and guidance. When I am alone, either because I have detached myself or because circumstances have wrenched me free, I seek first and most naturally to reestablish my relatedness. My very individuality is defined in a set of relations. This is my basic reality.²¹⁶

A decision to reject or accept the "I must" is a decision for which the physician is held accountable. MacIntyre says, "To be the subject of a narrative that runs from one's birth to one's

²¹⁵Noddings, p. 83.

²¹⁶Noddings, p. 51.

death is...to be accountable for the actions and experiences which compose a narratable life."²¹⁷ Accountability requires something more than declaring as did Drs. Schmal and Wilbur that, "I did my time," or "I've got to be selfish." Really caring about the self means caring about the ethical self. Noddings states, "We are not 'justified'--we are *obligated*--to do what is required to maintain and enhance caring. We must 'justify' not-caring; that is, we must explain why, in the interest of caring for ourselves as ethical selves or in the interest of others for whom we care, we may behave as ones-not-caring toward this particular other."²¹⁸

There is choice here, but it is not the free enterprise ideal of free choice of whom to serve. It is choice about the physician's ethical self, about the physician's story, about "whom to be...--or more accurately, whom to become,"²¹⁹ about the strands of thread that will be woven into the tapestry of the practice of medicine. Chekhov's Dr. Astrov has a revelation when a patient dies on whom he has worked without feeling or compassion. He realizes that the course he chooses today becomes the legacy of physicians tomorrow. "And just when I didn't need any feelings, my feelings woke up, my conscience was stricken, as if I had killed him deliberately...I sat down, closed my eyes--

²¹⁷ MacIntyre, p. 217.

²¹⁸ Noddings, p. 95.

²¹⁹ Lebacqz, p. 83.

like this--and I thought; those who will live one or two hundred years after us, and those we blaze the trail for now, will they remember us with a kind word?"²²⁰

In summary, the practice of medicine is grounded in relationship. It is in relationship that the physician is physician. Furthermore, it is through relationships past, present and future that the self is created, enhanced, expressed and realized. It is for this reason that Cassell can say about the physician, "...he can comfort and reassure in a manner so basic that it is related to experience in early infancy."²²¹ The primordial relationship also bears influence on the self as care-giver and care-receiver since it is part of "... a concept of self whose unity resides in a narrative which links birth to life to death as narrative beginning to middle to end."²²² It is also through the relationships between individual physicians and their patients that the tapestry of the practice of medicine continues to be woven.

The moral nature of the physician-patient relationship demands that the physician accept moral responsibility. Certainly the physician must accept moral responsibility for the care of patients with whom he or she is already in relationship, but now we see that this moral responsibility extends also to

²²⁰ Chekhov, Anton Pavlovich, Collected Plays, New York: Penguin, 1964. p. 188.

²²¹ Cassell, p. 139.

²²² MacIntyre, p. 205.

future patients including those with AIDS. To not extend responsibility in this way diminishes the physician's ethical ideal, a vision of the physician as good physician, which has consequences for the physician's capacity to care for those with whom the physician is presently in relationship and those yet to come.

Up until now with few exceptions physicians, lawyers and ethicists have examined the ethical obligation to care for patients with AIDS in terms of only one orientation to morality, that which emerges naturally from the concept of self in relation to others based on separation and objectivity. This is a morality defined in rules and standards of fairness.²²³ Searching for obligation in this manner leads to laws and codes and principles of ethical conduct and the absence of any unambivalent, straight-forward statement of obligation.

We have, however, seen glimpses of the threads of a different, care-based morality as they have been found within the tradition of medicine and have been woven into the unfinished tapestry of the practice of medicine. These threads come together most obviously in the 1988 joint statement of the American College of Physicians and The Infectious Diseases Society of America to which we stated earlier in Chapter 3 we

²²³ See Gilligan, Carol, In a Different Voice, Cambridge, Massachusetts: Harvard University Press, 1982; Gilligan, Carol, Ward, Janie Victoria and Taylor, Jill Mclean, eds., Mapping the Moral Domain, Cambridge: Harvard University Press, 1988; and Lyons.

would return. It states in part,

If medicine wishes to retain its respected status as the healing profession, we must continue to provide the best possible care to our patients, regardless of personal risk. To do less threatens the very nature of the patient-physician relationship, makes a mockery of our professional heritage, and violates the very essence of being a physician. (emphasis added)²²⁴

It is now clear that the essence, the fundamental construct, of being a physician, of participating in the practice of medicine, is relationship. Only in examining the ethical obligation to care for patients with AIDS in terms of the orientation to morality that emerges naturally from connection and is defined in caring can we come to know that obligation. It is the nature of the physician-patient relationship that is threatened when that essence is violated, and it is the practice as well as the individual practitioners that feel the effects of that violation. After all the searching, the ethical obligation does, in fact, exist within the practice of medicine.

The Ethos of Relationality

Why is it that the ethic of caring is not as clearly outspoken or as forcefully and primarily called to the forefront in the practice of medicine as is the ethic of rights? Why do physicians, unlike nurses, not automatically turn to an ethos of relationality, "the capacity or potential to experience other

²²⁴ Health and Public Policy Committee, 1988, p. 462.

persons,"²²⁵ to affirm their obligation to patients. Certainly this ethos has its place in the tradition of the practice of medicine. It is there in the words of the framers of the 1847 AMA Code of Medical Ethics who said, "A physician should not only be ever ready to obey the calls of the sick, but his mind ought also to be imbued with ... the responsibility he habitually incurs...."²²⁶ It is called to mind by the 19th century physician Worthington Hooker who said,

He enters the dwelling of the sick as if he were one of the family, and the very office that he is to perform disarms all formality, and pre-supposes intercourse of the most familiar character. The patient is to speak to him not of a foreign subject, nor of some one else, but of himself, of his own body, of its pains and ailments, and that too with sufficient minuteness to communicate an adequate knowledge of his case. In doing so, he calls into exercise not only the scientific acumen of the physician, but mingled with this, the sympathy of the confidential friend.²²⁷

This ethos is there in the writing of Peabody in 1927 who said, "The practice of medicine in its broadest sense includes the whole relationship of the physician with his patient."²²⁸ It is there in the every day thoughts and deeds of hundreds of physicians who are dedicated to caring for their patients. It is there as already noted in the writings of modern medical

²²⁵Powell, pp. 71-72.

²²⁶AMA Code of Medical Ethics 1847, p. 10.

²²⁷Hooker, Worthington, Physician and Patient; or, A Practical View of the Mutual Duties, Relations and Interests of the Medical Profession and the Community, New York: Baker and Scribner, 1849. p. 384.

²²⁸Peabody, p. 877.

ethicists, May, Cassell, Pellegrino, Ladd, and of Kass who says,

The call for rules, guidelines, and procedures; the convening of ethics committees; and the encouragement of statutory regulations are a search for yet one more technical solution--this time a technical ethical solution--for problems produced by our already foolish tendency to see technical medical solutions for the weighty difficulties of human life. If a doctor would be a physician and not merely a body technician, he must also be a knower of souls, those of his patients and, not least, his own.²²⁹

This ethos is not that of the hospital, however, the institution where medical students and beginning physicians are trained and socialized.

Institutional Socialization

In 1927 Peabody asked the question, "Can you form a personal relationship in an impersonal institution?"²³⁰ As stated earlier, an institution, as opposed to a practice, is primarily interested in the acquisition and distribution of external goods. A physician's investment in a patient is entirely different from a hospital's investment in a patient. The hospital, while it is concerned with the patient getting well, is concerned not with the patient's illness, but with the patient's disease, in the sense elucidated by Cassell. The hospital is concerned with time and efficiency and how these relate to cutting costs. This is not at all to say that physicians should not be concerned with cutting costs because, of course, they should be. Caring for the

²²⁹ Kass, p. 210.

²³⁰ Peabody, p. 880.

patient demands a sense of responsibility in regard to the patient's finances, but a sense of responsibility in regard to society is also demanded. However, physicians cannot be motivated primarily by concerns for efficiency and cost at the expense of care.

May believes that physicians' training emphasizes the technical skills aspect of the practice of medicine over that of relationship and caring. In the hospital, "The patient functions as locale for the disease--like a farmhouse on a battleground that acquires interest for the soldier only because of the enemy that may inhabit it. The cumulative impact of the training filters out the personal, not merely the patient as person but the physician as person."²³¹ Simenon's Maugras lying in his hospital bed wonders, "Wouldn't the ideal thing, for some doctors, be sickness without any sick men?"²³² This depersonalization of both patient and physician is a consequence of the pressures applied to the physician by the institutional setting emphasizing and rewarding institutional values.

Mizrahi explores the process of socialization of beginning doctors that she says is responsible for the forging of a professional consciousness steeped in the attitude that it is

²³¹ May, p. 98.

²³² Simenon, p. 37.

desirable to Get Rid Of Patients (GROP).²³³ This consciousness is diametrically opposed to the fundamental construct of the practice of medicine which has been identified as relationship. It leads to the characterization of patients as "gomers", "hits", "trainwrecks" and "dirtballs".

Mizrahi studied the house staff in the department of internal medicine in a large southern university medical center during the late 1970s and early 1980s. There she found that beginning physicians tired, frustrated and overwhelmed, instead of bonding with patients tended to bond with and desire the approval of other house staff members who already were socialized in the GROP perspective. Within this perspective, the patient was characterized as "the ultimate enemy."²³⁴ In his discouraging account of the process of becoming a physician, Konner concurs. "It is obvious from what I have written here that the stress of clinical training alienates the doctor from the patient, that in a real sense the patient becomes the enemy."²³⁵ Konner goes so far as to suggest that meeting the demands of institutional medicine requires more than objectivity and detachment from the patient, it "...may actually require a measure of dislike."²³⁶

²³³Mizrahi, Terry, Getting Rid of Patients: Contradictions in the Socialization of Physicians, New Brunswick, New Jersey: Rutgers University Press, 1986.

²³⁴Mizrahi, p. 33.

²³⁵Konner, Melvin, Becoming A Doctor: A Journey of Initiation in Medical School, New York: Penguin Books, 1988. p. 373.

²³⁶Konner, p. 373.

In Mizrahi's study the approval of the peer group was bestowed on those members of the house staff not who cared but who could "turf", "dump" or in other ways work efficiently to reduce the patient load. While reduction of the patient load was desirable to reduce the workload, the administrative emphasis on turnover of beds also was a factor in this attitude. One house staff member was overheard commenting that he had fewer patients than another which showed that he was better at getting rid of people. Mizrahi points out, "This comment reveals an unspoken truth about the hierarchy of internal medicine: status within the profession is determined by distance from patients and the freedom to choose among them."²³⁷ It is a truth confirmed by a physician doing a fellowship in medicine who half-jokingly remarked, "The best thing about becoming a fellow is that you only have to see the patient once, and then all you have to do is look at the numbers."²³⁸

Mizrahi found that there are many strategies employed by house staff to get rid of patients or to distance themselves. One is avoidance. Interacting directly with patients was given relatively short shrift in a day filled with making phone calls, scheduling appointments, writing notes, filling out forms, transporting patients, preparing for, conducting or following up on rounds.

²³⁷ Mizrahi, p. 37.

²³⁸ This point was made by a fellow on rounds to several medical students.

Another strategy is objectification whereby the patient is treated as a non-person. Noddings says that treating people as "types" instead of persons turns them into "cases". "The fact is that many of us have been reduced to cases by the very machinery that has been instituted to care for us."²³⁹ Simenon's Maugras is treated this way. "Glances were exchanged, as at the start of his illness. Of course, he was not in on the secret. What was happening had nothing to do with him, even if it was happening to him, in his own body."²⁴⁰ Mizrahi finds that, "Treating patients as absent when they are physically present denies the existence of the human subject. By treating most patients as subjectless objects, the house staff eliminated them as active participants in patient care in spite of increasing data on the importance of patient involvement."²⁴¹ It was more likely that patients treated in this manner were from social groups or had diseases that house staff found objectionable. It is a mode of behavior easily accessible to physicians caring for patients with AIDS.

Mizrahi found that the house staff "...learned that to spend extensive time engaged in the doctor-patient relationship went unrewarded and indeed might even lead to sanctions from their mentors if activities more important in the latter's eyes

²³⁹Noddings, p. 66.

²⁴⁰Simenon, p. 90.

²⁴¹Mizrahi, p. 99.

were ignored or postponed."²⁴² One activity that was often given less attention as the house staff progressed through their training was history taking--hearing the patient's story. A resident remarked, "If you don't sit and talk with the cancer patient for a half hour, in terms of your job description and what's expected, nobody will be upset with you. But if you don't know what the hemoglobin is on that patient, they...are going to be very upset."²⁴³

Other barriers to establishing physician-patient relationships included the frequent change in assignment to services to allow for greatest exposure to a wide variety of patients. In addition, house staff complained that they infrequently observed more than "fleeting" interaction between attendings and patients, and "...when humanistic behavior was manifested by a few attending physicians, it was perceived as either the exception to the rule or an artifact of the attendings' privileged removal from everyday patient care."²⁴⁴

Beginning physicians can be denied much access to established physicians who find strength and gratification in the physician-patient relationship. Furthermore, this denial may directly impact on the attitudes a new physician may develop towards patients with AIDS. Cooke and Sande state, "Many

²⁴²Mizrahi, p. 94.

²⁴³Mizrahi, p. 94.

²⁴⁴Mizrahi, p. 111.

trainees, working in settings in which no one can articulate the complex medical ethic and where prestigious faculty members see few patients, are deprived of the example of practitioners resolving the tensions between perceived personal risk and potential benefit to the patient."²⁴⁵ They emphasize the powerful positive impact of exposure to "...the clinician-teacher providing hands-on AIDS care."²⁴⁶ Five years after Mizrahi's original study, those house staff who elected to enter academics and who were likely to become attending physicians themselves, in general, "...were distanced from patients and overall tended to characterize their relationships with patients less humanistically than private practitioners but better than house staff."²⁴⁷

Ultimately, the house staff followed in Mizrahi's study made career decisions based on their needs and in relation to the experiences they had while house staff. Interestingly, all the house staff felt that their relationships with their peers were the most important during their training years. It is little wonder that many physicians consider their allegiance to co-professionals a solemn commitment. That relationship, at least,

²⁴⁵ Cooke, Molly and Sande, Merle A., "The HIV Epidemic and Training in Internal Medicine," The New England Journal of Medicine, November 9, 1989, 321:1334-1337. p.1335.

²⁴⁶ Cooke and Sande, p. 1337.

²⁴⁷ Mizrahi, p. 150.

is well-developed by the end of the training years.²⁴⁸

Relationships with patients were held in different regard.

Mizrahi found,

Career choices are often a reaction against the conditions experienced in the training context. Doctors have learned to view patients most benignly as boring and intrusive, at worst, as candidates for avoidance. At the end of training, doctors desire to recapture what remains of a personal life, acquire the social status and concomitant social privilege that is the reward for their service and sacrifice, control the conditions of their labor, and regulate their relationships with patients, for in their training, patients have come to embody a recalcitrant and exploitive system.²⁴⁹

It is sad and unfortunate that beginning physicians in boot camp medical training are denied much of a view of the essence of medicine, the one thing that could positively sustain them as they make it through the trials of those years. Patients are everywhere around them. Instead of circling the wagon trains to keep the enemy out, beginning physicians need to draw the circle larger, to encompass patients as those cared-for and to come to know themselves as ones-caring. In this way, physicians can, through caring, responsible relationship acquire the internal goods of the practice of medicine, one of which is self-realization, instead of longing only for the external goods of status, privilege and income.

²⁴⁸It is a digression but not irrelevant to note that the refusal to care for patients with AIDS may damage the relationship of physicians with their colleagues also. The fewer physicians who care for patients with AIDS, the greater the risk to those that do. The new "plague doctors" are accepting a concentrated risk of infection that ought to be diluted among most physicians.

²⁴⁹Mizrahi, p. 135.

A step in this direction will be taken when the validity of the ethic of caring in the practice of medicine is recognized; when the ethos of relationality found within the tradition of the practice of medicine is heralded and made an integral part of medical student and house staff training; and when those responsible for the training of new physicians take seriously the destructive domination of institutional values over those of the practice of medicine. Then the motivational stories told about the "good" house staff, the lore of the hospital, can become stories of receptivity of patients rather than avoidance. Then the ethical ideal born in stories of relationship will be nurtured in stories of the institution.²⁵⁰

²⁵⁰There are many other important questions deserving serious consideration that are related to the question asked here but are beyond the scope of this thesis. First, what obligation does the institution incur to minimize the risks of infection from AIDS to house staff and other health care personnel? Hospitals have responded by providing latex gloves and needle disposal boxes in most rooms and by attempting to enforce universal body fluid precautions, however, there is more that can be done. Does the institution's emphasis on efficiency and cost-saving sometimes come in conflict with minimizing risk? For example, some procedures such as arterial blood gas drawing still require handling the needle after it has been in contact with a patient's blood. Does the hospital have an obligation to pursue the availability of self-capping needles even at increased expense? Furthermore, the very same emphasis on efficiency and getting things done in a hurry that leads to avoidance of patients may also lead to disaster. One medical student who stuck herself with a needle recalls feeling hurried and pressured to "Draw the blood and be quick about it." It stands to reason that accidents are more likely to happen when physicians are tired and pressured. Cooke and Sande point out, "Preventable stress due to overwork, lack of sleep, and the impairment of supportive personal relationships should be confronted and relieved by reforms in training. Many of these proposals are valid independently of AIDS; perhaps the HIV epidemic will provide the impetus for their implementation."(Cooke and Sande, p. 1337)

Another important question that warrants attention is what

Rejection of the "I Must"

For a moment, let us return to the concept of the ethical self and how it is enlarged and enhanced through attention to the "I must". The obligation to care for patients with AIDS has been affirmed in the moral responsibility that stems from the caring relationship of physician for patient, however, one point has yet to be addressed. Is it always morally wrong to reject the "I must"? Can there ever be extenuating circumstances that would require one to say, "I cannot care for this patient with AIDS?"

is the institution's obligation in the event a health care worker seroconverts due to an accident while caring for a patient with AIDS? In a letter to the editor of a journal, Henry asks, "Can health care workers keep their jobs if they seroconvert to HIV positivity at work? Who will pay for prophylactic zidovudine if a health care worker receives a needle stick? Will health care workers have to pay higher insurance premiums if they care for patients with HIV?" (Henry, Keith, "Do Physicians Have an Obligation To Treat Patients with AIDS?" [Letter] The New England Journal of Medicine, January 12, 1989, 320:120-121.)

Aoun, a medical resident, poignantly writes about his own experience after contracting AIDS from a patient. "What followed was nearly as painful as the illness itself. For many months, hospital officials refused to acknowledge that I had contracted AIDS while caring for an infected patient. In addition, no job assurance was provided, and my contract was not renewed." (Aoun, Hacib, "When a House Officer Gets AIDS," The New England Journal of Medicine, September 7, 1989, 321:693-696. p. 695.) Certainly physicians should not have to fear punishment at the hands of the institutions they serve for behaving well.

In spite of it all, however, this physician who acquired AIDS from his patient and who personifies confirmation of our worst fears, recognizes, "Compassion, concern, and support are crucial for relieving some of the overwhelming pain of the victims of AIDS, as well as for prolonging life and improving its quality. What has helped me most during my hospitalizations is the fighting attitude of my physician; the fact that he has never given up has helped me not to give up.... It gives me great sadness that many patients who have AIDS do not have this kind of support." Having become a patient himself, ironically he concludes, "Health care workers must not deny care to the victims of this complex human nightmare." (Aoun, p. 696.)

Indeed, might there not be a conflict between one's relationship with patients and one's relationship with the more intimate cared-for in a closer circle, for example, one's family? One can certainly be part of more than one practice. As MacIntyre puts it, "Someone may discover ... that he or she is a character in a number of narratives at the same time, some of them embedded in others."²⁵¹

The Massachusetts licensing regulations stipulate that one possible exception to the duty to care for patients with AIDS might be in the case of a pregnant physician treating a patient with cytomegalovirus. Many newborn intensive care units recognize this exception and post signs warning pregnant caregivers in cases where a baby is known to be shedding cytomegalovirus. In such a case, a pregnant caregiver may have to excuse herself from performing certain procedures that might place the unborn fetus at increased risk. Another example of a situation exempting a physician from caring for a patient with AIDS would be in the case of a physician without immunity to varicella zoster virus (VZV) who is assigned to care for a patient with herpes zoster.

HIV positive patients frequently suffer from herpes zoster.²⁵² Varicella zoster, chicken pox, may result from

²⁵¹MacIntyre, p. 213.

²⁵²Cohen, Philip R. et al, "Disseminated Herpes Zoster in Patients with Human Immunodeficiency Virus Infection," The American Journal of Medicine, June 1988, 84:1076-1080.

exposure to these patients in a physician who lacks immunity to the disease. Chicken pox is highly contagious and has an incubation period of 10 to 21 days, the last few days of which the host is infectious but asymptomatic. An infectious physician may be a threat to other immunocompromised patients or to immunocompromised family members and friends. Furthermore, "Perinatal varicella is associated with a high mortality rate when maternal disease develops within 5 days before delivery or 48 hours post partum."²⁵³ Therefore, this threat may extend to one's unborn child directly or through infecting one's pregnant spouse. In an ethic of caring and responsibility, only the one-caring can decide responsibly what action will enhance and what action will diminish the ethical self. To put oneself in a position where harm would likely come to other cared-fors would not enhance that physician's ethical self. It is important to remember that the ethical ideal is not a rule or regulation that can be invoked. According to Noddings, "The one-caring, clearly, applies 'right' and 'wrong' most confidently to her [sic] own decisions. This does not...make her a relativist. The caring attitude that lies at the heart of all ethical behavior is universal."²⁵⁴

²⁵³Braunwald, Eugene et al, eds., Harrison's Principles of Internal Medicine Eleventh Edition, New York: McGraw-Hill Book Company, 1987. p. 690.

²⁵⁴Noddings, p. 92.

A decision such as this physician's is based on facts available to him or her at a particular instant in time. The decision not to care for a particular patient with AIDS who is known to have herpes zoster does not mean that he or she will not care for all patients with AIDS and it does not mean that he or she will not care for this patient under different circumstances; it is subject to change with a change in facts. Once the patient is no longer infectious or the physician proves to be immune to VZV, he or she re-evaluates the decision. Then, enhancement of the ethical self will require a different response. Under all circumstances, the decision is grounded in caring relationship. Deciding to reject the "I must" in this way is altogether different from a blanket refusal to care for patients with AIDS out of fear that to do so may somehow threaten one's family. Noddings states, "Feeling, thinking, and behaving as one-caring mark ethical behavior; but when caring must retreat to an inner circle, confine itself, and consciously exclude particular persons or groups, the ideal is diminished, that is, it is quantitatively reduced."²⁵⁵

²⁵⁵Noddings, p. 114.

Chapter 8: Conclusion

In conclusion, there is an ethical obligation to care for patients with AIDS. It is grounded in the potent essence of the practice of medicine, in the physician-patient relationship. This is a caring relationship wherein the physician comes to know the patient through attention to the patient's story and body. This relationship carries with it responsibility to act always with concern for the well-being of the patient. Furthermore, this responsibility extends to those patients yet-to-come, those with whom there is the potential for relationship. The imperative to care for these others rests on a vision of the self as an ethical one-caring created, enhanced and realized in relationship, diminished and violated in rejection of relationship, and held accountable in the story of oneself as physician.

The unfinished tapestry of the story of the practice of medicine depends on these threads of physicians' stories to be woven into its rich tradition. Then physicians will be able, as Arras explains, to

...proceed to tell a story, to relate a history, of a profession that has incorporated a willingness to take risks for the benefit of patients as a constitutive element in physicians' self-understanding. Over time, this account would explain, the profession elevated the ideal of steadfast devotion to the well being of patients to the status of a fundamental duty, a definitive element inherent in the very role of physician. According to this story, physicians, if queried about their commitment to accept risk in the line of duty, would simply respond, "This is who we

are; this is what we do...."²⁵⁶

As Arras points out, "Incredibly, however, this is a history that has yet to be written."²⁵⁷

It is up to this generation of physicians to acclaim an ethos of relationality standing shoulder to shoulder with past and future generations of physicians. That is, after all, an important aspect of the Hippocratic Oath. As discussed in Chapter 3, the value of the Oath for our purpose lies not in its literal meaning but in the symbolic meanings ascribed to it by the swearer. We can choose to find in the Oath an ethos of relationality if we accept Kass's interpretation that the statement, "Whatever houses I may visit, I will come for the benefit of the sick..." refers to the physician entering the "intimate life-world" of the patient.

Nevertheless, the code can provide the type of connection upon which human beings depend. That is the value of tradition and of ceremony. It connects physicians of today with physicians of past centuries and physicians of future centuries. Recalling one's place in the unfolding human story is why people cry at weddings and graduations and why after 25 years people flock to school reunions. People crave relationship and connection. People need to see themselves in touch with others, holding hands with a long line of people extending back into the past and

²⁵⁶ Arras, p. 13.

²⁵⁷ Arras, p. 13.

forward into the future. As Cassell points out, it is in connection that we know we are alive.

It is up to this generation of physicians to acknowledge the value of relationship in the practice of medicine, to fight for its preeminence in the education of new physicians and to be sure that it is relationship that is affirmed in tradition. It is up to this generation of physicians to acknowledge the validity of feelings in the practice of medicine and to know that a way of behaving may feel right because it may be right. Noddings states, "Thus, at the foundation of moral behavior...is feeling or sentiment. But, further, there is commitment to remain open to that feeling, to remember it, and to put one's thinking in its service."²⁵⁸

Finally, it is up to this generation of physicians inspired by the challenge of AIDS to clearly articulate its commitment so that future generations will come to the practice knowing without confusion what Dr. Rieux in The Plague knew,

...that the tale he had to tell could not be one of a final victory. It could be only the record of what had had to be done, and what assuredly would have to be done again in the never ending fight against terror and its relentless onslaughts, despite their personal afflictions, by all who, while unable to be saints but refusing to bow down to pestilences, strive their utmost to be healers.²⁵⁹

²⁵⁸Noddings, p. 92.

²⁵⁹Camus, p. 287.

Postscript: Stories

I must say a few last words about the excerpts from patients' stories that have appeared throughout this paper. These stories represent people like all other people, fearful, hopeful, thoughtful, connected. They show clearly that AIDS is a disease of relationships, children not able to confide in parents, lovers fearful of harming lovers, families soon to be torn apart. If physicians refuse to care for patients with AIDS or do so with less than their usual enthusiasm, the disease takes with it one more relationship.

One may say that my choice of stories shows bias. I could choose those that are poignant or appealing or that make my point. I cannot refute this claim. I can only reply, in refusing to receive patients with AIDS, one loses the opportunity to choose, one loses the opportunity to be touched by any story.

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