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Physicians' Responsibilities in the Treatment of AIDS Patients

By

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THESIS

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Chair Date

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PHYSICIANS' RESPONSIBILITIES IN THE TREATMENT OF AIDS PATIENTS

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Elizabeth Riggs McCarthy

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The large and rapidly increasing numbers of HIV-infected patients needing medical care today present the medical profession with many unprecedented challenges. These challenges exist both within the scientific arena, and within the realm of ethics and professional responsibility. One of the most basic issues AIDS poses is whether a physician may refuse to treat a patient when that patient poses some risk to the physician.

Scattered instances of physicians categorically refusing to treat AIDS patients have brought this question into focus. However, overt refusal represents only the extreme and least prevalent response on a spectrum of avoidance and fear of AIDS patients by physicians. Far more physicians are reluctant to treat AIDS patients, or treat patients with a great deal of fear, than refuse to treat AIDS patients at all.

Responses to reports of physician reluctance to treat HIV-infected patients have been mixed. Much of the debate has centered on the amount of risk involved in treating AIDS patients. Many individuals have condemned the "irrational," "unrealistic," "unreasonable," "almost hysterical" fears of HIV contagion in the medical care setting as "unsupported by medical evidence."[1] Studies have characterized the chances

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[1] Kevin Kelly, "AIDS and Ethics: An Overview," General Hospital Psychiatry 9(1987):331-340.

of contracting AIDS occupationally as "minuscule" and "vanishingly small." Many doctors have responded that the risk is not so small--indeed that it is unacceptably high. Much of the debate thus has focused on defining excessive versus acceptable risk of occupationally-acquired HIV infection.

Some writers have concluded that because the occupational risk of HIV is so small, prejudice motivates physicians' reluctance to treat HIV-infected patients.[2] Others have accepted that physicians have refused to treat AIDS patients out of fear, but have put forth a "call to duty"--arguing that physicians must treat HIV-infected patients because physicians have always continued their work in times of epidemic disease; because being a professional demands that they do so; because the nature of the doctor-patient relationship requires such a duty; or because the act is a requirement of a virtuous person.[3] Physicians' responses to colleagues who do not want to treat AIDS patients vary. Many physicians often simultaneously hold strong beliefs that HIV-infected patients must be cared for, and that physicians have the right to refuse to treat these

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[2] Joseph Reiner, "AIDS Discrimination by Medical Care Providers: Is Washington Law an Adequate Remedy?" Washington Law Review 63(1988):701-724.

[3] See Eric Loewy, "Duties, Fears and Physicians," Social Science and Medicine 22(12):1363-1366; John Arras, "The Fragile Web of Responsibility: AIDS and the Duty to Treat," Hastings Center Report April/May, 1988, 10-19.

patients.

Thus the issues surrounding AIDS treatment can be framed in differing ways. Are we dealing with an unethical group of professionals who wish all the benefits of being physicians while seeking to avoid even the smallest personal risk? Is all the hoopla about physician safety really a cover-up for homophobia and value judgments about the worth of HIV-infected patients' lives? Or is the issue one of autonomy rights for physicians? Should physicians be allowed to protect themselves from a deadly disease? Must they take the risk of dying of occupationally-acquired AIDS? What are the "real" issues involved in physician reluctance to treat AIDS patients?

This paper attempts to expose the more problematic aspects of the debate about AIDS treatment, and to discuss the issue in a way that does justice to its complex nature. Parts I, II and III discuss why AIDS has been defined as an occupational risk and how physicians perceive that risk. These sections conclude that characterizing the risk of occupational AIDS as "minuscule" is a far too simplistic method of understanding physicians' fears of AIDS transmission. Since characterizing the risk as "small" is an oversimplification of a complex phenomenon, it is not clear that physicians should be required to take care of AIDS patients only because the risk is so small. Since such a duty cannot be derived from the small magnitude of the

occupational risk, Part IV looks at historical notions of medical professionalism and the doctor-patient relationship and their differing implications for physicians' responsibilities in the AIDS epidemic. It concludes that because multiple competing models of medical professionalism and doctor-patient relationships exist, any one is an inadequate basis for developing professional ethics regarding treating AIDS patients. Finally, Part V suggests that until now those who fear contracting AIDS occupationally have delineated the question of whether a physician may refuse to treat an AIDS patient as an individual issue. In this formulation, each member of the profession has her own set of risks, depending on her practice; she must decide, as an individual, whether she is willing to accept these risks. This formulation of the issue is problematic. Implicit in every code of professionalism is a sense of reciprocal obligation between doctors, a sense of professional community. Part V suggests that the issue of physicians' responsibilities to AIDS patients should be defined as one to which the community as a whole should respond, since there is no way for an individual doctor to avoid risk of occupational AIDS without increasing another doctor's risk. It offers suggestions on how to reduce physicians' fears of occupational HIV transmission, and thereby reduce the incidence of refusals to treat AIDS patients. These suggestions are based upon a

call for a renewed sense of professional community and on institutional support for those providing AIDS care.

PART I: WHAT FACTORS MOTIVATE A REFUSAL TO TREAT?

A. Physicians' Attitudes Towards Homosexual Patients and Patients Infected with HIV.

The same proportion of health care workers have AIDS as the total labor force, and 95.1% of those health care workers with AIDS have a risk factor for HIV infection unrelated to employment.[4] Clearly, large numbers of health care workers have not become infected on the job to date.[5]

There is much controversy within the society and within the medical profession as to how much of a refusal to treat an HIV-positive patient is a result of prejudice, and how much is a result of fear. Clearly, the amount of fear and prejudice in the decision of any one individual is difficult to quantify. Fear can increase prejudice and prejudice can inform fear. In addition, the two feelings may act synergistically; a doctor might be fearful of treating an HIV-positive patient, but might be able to overcome her fear enough to do so. However, her additional disapproval of the lifestyle of a homosexual man or intravenous drug abuser may, when combined with her fear, be enough to make her refuse to treat such a patient. In addition, the stigma of

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

[5] For more information on the risks of HIV transmission in the health care setting, see pg. 47.

AIDS infection per se may elicit harsh reactions by physicians, unrelated to physicians' attitudes towards homosexuality or drug abuse.[6]

Fear and prejudice towards AIDS patients can also influence a doctor's perception of her competence to treat a patient with AIDS.[7] Dr. Cooke at San Francisco General Hospital suggests that often AIDS care is straightforward, and many referrals for ostensibly medical reasons may be motivated in large part by psychological factors.[8] Does the physician's fear of AIDS for whatever reason, make her quicker to refer? Are many referrals of AIDS patients on medical grounds then not justified?

On the other hand, we should also be careful about jumping to the conclusion that a refusal to treat an HIV-infected patient is necessarily an unethical act. As Dr. Day at San Francisco General Hospital puts it, "HIV infection has become an absolute indication for surgery." Surgeons may feel pressured to do operations on HIV-positive patients for fear of being labeled "homophobic" or "discriminatory." In our rush to be fair to patients, let

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[6] Jeffrey A. Kelly et al., "Stigmatization of AIDS Patients by Physicians," American Journal of Public Health 77(7):789-791.

[7] Molly Cooke, M.D., Chair, Ethics Committee, San Francisco General Hospital. Grand Rounds, University of California, San Francisco, January 19, 1989.

[8] Molly Cooke, "Ethical Issues in the Care of Patients with AIDS," QRB October 1986, 343-346.

us not forget that there are many instances in which a particular procedure will not significantly benefit the patient and may in fact cause him some harm. For instance, many fewer lung biopsies are being done on patients suspected of having pneumocystis carinii pneumonia. One reason for this decrease may in fact be physicians' reluctance to expose themselves to the risk of infection, solely to confirm an already overwhelmingly likely diagnosis (although this is by no means clear). However, does that mean that the decreased number of biopsies is bad medicine? To the contrary, it may be better medicine; the patient is treated promptly and not subjected to an invasive procedure done solely to nail down the diagnosis.

With these qualifications in mind, we can turn to various studies of the extent of homophobic attitudes, stigmatization of AIDS patients, and fear of AIDS contagion within the medical profession. Various studies have attempted to ascertain the amount of homophobia in the medical profession. A study undertaken before AIDS was linked to homosexual behavior found 22.9% of responding physicians in San Diego to be homophobic.[9] The percentage of homophilic, neutral and homophobic physicians varied markedly among specialties. In general, psychiatrists,

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[9] Wm. Christopher Mathews et al., "Physicians' Attitudes Toward Homosexuality--Survey of a California County Medical Society," Western Journal of Medicine 144(1986):106-110.

pediatricians, and internists were the most homophilic, while orthopedic surgeons, gynecologists, family practitioners, and surgeons (excluding orthopedists) in decreasing order expressed the most homophobic attitudes. Another study of house officers and nurses in an urban teaching hospital reported a significant level of homophobia in respondents.[10] One of 37 physicians and 11 of 90 nurses agreed with the statement "homosexuals who contract AIDS are getting what they deserve."

One interesting finding in these studies is the fact that surgeons, and in particular orthopedic surgeons, rank highest in their homophobic attitudes. What are we to make of this information in the light of the predominance of surgeons in the group of physicians reluctant to treat HIV-positive patients? Surgeons probably do have a higher risk of contracting HIV occupationally, but is their fear of contracting HIV completely unrelated to the higher prevalence of homophobia in these specialties? Or is the fear a product of this homophobia? Studies of homophobia among physicians highlight the difficulties in ascertaining the primary motivation behind any one physician's refusal to treat an HIV-infected patient.

Prior to AIDS being labeled a "homosexual disease,"

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[10] Carolyn J. Douglas et al. "Homophobia Among Physicians and Nurses: An Empirical Study," Hospital and Community Psychiatry 36(12):1309-1311.

physicians stigmatized homosexual patients. Though physicians may stigmatize AIDS patients because they are predominantly homosexual men (in San Francisco), AIDS may have now acquired a stigma of its own which contributes to homophobic attitudes.[11] Studies of physicians' attitudes towards patients with AIDS and physicians' willingness to associate with these patients, even socially, have reported different results; some have found that physicians do stigmatize AIDS patients, and others have not. Kelly and colleagues distributed two vignettes about a fictional patient to a group of physicians in Ohio, Arizona and Tennessee.[12] The vignettes differed only in identifying the patient's illness as either AIDS or leukemia, and the name of the patient's romantic partner as Robert or Roberta. Though physicians were on the whole sympathetic to the suffering of AIDS patients, they considered the AIDS patient in the vignette to be more responsible for his illness, more

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[11] However, the care of AIDS patients is quite different than caring for a person infected with HIV, but who has not developed AIDS. Treating patients with AIDS is a draining and difficult emotional experience. It requires an intensive relationship with a dying person who is often the same age as the doctor, and there is little the doctor can do to stop the relentless progression of the disease. Doctors may wish to avoid such continuous draining experiences, but would still treat patients infected with HIV who had not yet developed AIDS, and thus it is not easy to say that doctors who wish to avoid treating AIDS patients, as opposed to asymptomatic HIV-positive patients, are doing so because they stigmatize these patients.

[12] Jeffrey A. Kelly et al. "Stigmatization of AIDS Patients by Physicians," American Journal of Public Health 77(7):789-791.

deserving of what happened to him, to be experiencing more pain but less deserving of sympathy and understanding, and as more dangerous to others than the leukemia patient. They were less willing to attend a party at which the AIDS patient was present, and less willing to simply hold a conversation with the AIDS patient. They thus seemed more reluctant to have even social contact with an AIDS patient than a leukemia patient.

On the other hand, Richardson found that 61% of a sample of both homosexual and heterosexual Los Angeles physicians moderately or strongly agreed with the statement, "I would attend training sessions so I could treat AIDS patients."[13] Many physicians were willing to treat AIDS patients, and wanted more training to prepare themselves. The study found no evidence that physicians were prejudiced against homosexuals or people with AIDS and therefore unwilling to treat them. The contradictory results of the above studies suggest that a range of opinions about treating AIDS patients exists within the medical profession. We cannot assume that reluctance to treat these patients is necessarily based solely on fear, or solely on homophobia, nor can we assume that physicians are somehow "above" irrational fears or homophobic attitudes. Reluctance to

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[13] Jean L. Richardson et al., "Physician Attitudes and Experience Regarding the Care of Patients with Acquired Immunodeficiency Syndrome and Related Disorders," Medical Care 25(8):675-683.

treat AIDS patients appears to be the product of complex interactions of different attitudes.

B. Extent of the Fear of Occupationally-Acquired HIV Infection

Anecdotal reports abound about the tremendous fear some physicians feel when treating AIDS patients.[14] Most of the physicians I spoke to at different Bay Area hospitals felt that presently or at some time in the past five years, fear of HIV contagion had been quite prevalent at their hospital.[15] Though many felt that the fear had diminished on the medicine services, most felt that fear was still prevalent among surgeons. Other doctors spoke to me of their personal fears of AIDS. One doctor told me of a friend, an orthopedic surgeon, who said, "I'm too afraid. My hands shake when I'm around an AIDS patient. I can't operate". Others spoke of looking at the needle they had just withdrawn from an AIDS patient and thinking "this is a deadly weapon." One doctor told me she prayed as a resident that the AIDS patient on her unit wouldn't "code" on her shift, and thought "thank God for interns", since she could have them make the resuscitation efforts. These fears are

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[14] See Carol Pogash, "Bad Blood," San Francisco Chronicle, 15 January 1989, Image Magazine Section.

[15] See Appendix for sample and methods.

not made-up excuses for refusing to treat an AIDS patient; doctors' hands shake, they have nightmares, they pray that situations will not arise that will require that they expose themselves to AIDS. Clearly fear must be involved in many instances of treatment avoidance by physicians.

A 1985 study by Link[16] found a high level of fear of AIDS contagion in pediatric and medical house officers at seven New York hospitals with significant AIDS patient populations and excellent reputations for the quality of care they delivered to AIDS patients.[17] Forty-eight percent of the medical and 30% of the pediatric house officers had moderate to major concern about acquiring AIDS from patients.[18] Eighty percent of the house officers estimated their probability of getting AIDS from their patients to date was 1 in 10,000 or less. Those with needlestick exposures did not estimate a higher numerical risk than others. These risk assessments were actually

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[16] R. Nathan Link, "Concerns of Medical and Pediatric House Officers about Acquiring AIDS from Their Patients," American Journal of Public Health 78(4):455-459.

[17] In most hospitals, house officers are dismissed from their residency programs if they refuse to treat HIV-positive patients.

[18] The lower percentage of pediatric house officers who were fearful of getting AIDS from their patients may reflect less prejudice on the part of pediatric house officers towards children (young, innocent, lovable), but is more likely to reflect the smaller share of their time spent treating patients with AIDS, and the smaller number of patients with AIDS they saw (3-5% of total inpatients and 10% of their time versus 15% of inpatients and 25% of their time for medical house officers). In addition, pediatric house officers experienced fewer needlesticks.

lower than some estimates derived from epidemiologic data. Thus we cannot say that their high level of fear was based on inflated estimates of risk.

Only 11% of the house officers felt moderately or extremely resentful at having to care for AIDS patients, while 51% did not feel resentful at all. Two-thirds of the house officers felt that concern about acquiring AIDS didn't adversely affect patient care at all. However, twenty-five percent would not continue to care for AIDS patients if given a choice. Thirty-six percent of the medical house officers planned to make a career choice that was less likely to involve care of AIDS patients.

Because this study involved such an intensively exposed group of doctors, who were required to treat AIDS patients, it may overestimate the levels of fear, and the desire not to work with AIDS patients. It nevertheless documents that fear is prevalent within the profession, and that the fear is strong enough that it may contribute to doctors moving away from areas and specialties in which lots of AIDS care is required. It also suggests that doctors can be fearful about acquiring the infection, while at the same time not resenting the patients who present the threat.

C. Physician Attitudes About a Right to Refuse to Treat HIV-Infected Patients

Many physicians to whom I spoke felt that though AIDS patients must be treated, individual doctors should not be forced to treat HIV-infected patients. Some physicians have been willing to treat the HIV-infected patients whom their colleagues have refused to treat, thereby increasing their own risk, while simultaneously supporting their colleagues' rights to refuse to treat HIV-infected patients. Some members of the medical profession feel that if access to care can be assured for HIV-infected patients, individual doctors should be able to decide for themselves whether they are going to treat HIV-infected patients. Their highest priority is assuring individual autonomy, even at the price of increasing their own risk of contracting HIV occupationally.

In 1988 the New Jersey State Board of Medical Examiners initiated an AIDS policy which states that New Jersey physicians cannot categorically refuse to treat an AIDS patient with a problem within their realm of competence. Even in light of this policy, 50% of New Jersey physicians felt that such a policy was unnecessary, and 51% believed the New Jersey Board of Medical Examiners had no right to

enforce such a policy.[19] Fifty percent of physicians believed that they had the right to refuse to treat AIDS patients, and 20.4% would actually do so. However, 42.5% of the physicians would be willing to see more AIDS patients.

Doctors may hold a strong belief about their own rights to refuse, while at the same time treating both their own AIDS patient population and that of their colleagues. We cannot assume that doctors are likely to refuse to treat AIDS patients simply because they believe they have such a right. Nor can we assume that doctors who are willing to take on the added burden of caring for the HIV-infected patients of a colleague who has refused to treat them are likely to appreciate measures requiring physicians to treat AIDS patients.

D. Is Treatment Refusal Likely to Restrict Access to Medical Care for AIDS Patients?

The response of physicians to the AIDS epidemic has been filled with contradictions. The overwhelming majority of physicians have not overtly refused to treat HIV-infected patients.[20] The few physicians who have refused publicly to

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[19] IM--Internal Medicine for the Specialist, "Contradictions in a Crisis: New Jersey Physicians' Attitudes on AIDS," IM--Internal Medicine for the Specialist 10(1):107-120.

[20] Everett Koop, "Challenge of AIDS," American Journal of Hospital Pharmacy 45(3):537-540.

treat AIDS patients have received disproportionate media attention.[21] Various studies have suggested that many physicians want more training to enable them to treat AIDS patients, and a large percentage of physicians are willing to treat more AIDS patients than they currently do.[22]

Nevertheless, many physicians feel strongly that they do have a right to refuse to treat AIDS patients, and a significant minority say that they would refuse in certain situations.[23] A number of physicians at different Bay Area hospitals have spoken to me both about occasional overt refusals, and about subtler forms of denying care. Some physicians make it clear to individual patients with AIDS that they do not wish the patient to return to them for follow-up care.[24] Others have refused to treat AIDS patients, but because their colleagues have agreed to take

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[21] Carol Pogash, "Bad Blood," San Francisco Chronicle, 15 January 1989, Image Magazine Section.

[22] Jean L. Richardon et al., "Physician Attitudes and Experience Regarding the Care of Patients with Acquired Immunodeficiency Syndrome (AIDS) and Related Disorders (ARC)," Medical Care 25(8):675-683; IM--Internal Medicine for the Specialist, "Contradictions in a Crisis: New Jersey Physicians' Attitudes on AIDS," IM--Internal Medicine for the Specialist 10(1):107-120.

[23] Ibid.

[24] It is difficult to define what constitutes a "refusal" to treat. Is a physician who does not attempt to learn about AIDS so that she may avoid treating patients with AIDS "refusing" patients? Is a doctor who projects a negative attitude toward patients with risk factors for HIV infection "refusing" to treat a (possibly) HIV-infected patient?

on the refusing physician's AIDS patients, access to care for these patients has not been compromised. Certain physicians are taking on a disproportionate number of AIDS patients because others are avoiding treating AIDS patients. This situation may lead to tension between colleagues, but it does not necessarily mean that care is not available for AIDS patients. However, if the physicians who are taking on a disproportionate share of the workload decide that they are no longer willing to do so (a likely scenario in the face of rapidly rising numbers of AIDS patients) a real crisis in access to care could occur.

Even if no overt refusals occur in the future, access to health care for AIDS patients could be compromised simply by a lack of health care personnel in areas and specialties which have large AIDS patient populations. The nursing shortage is already a crisis; AIDS is likely only to exacerbate the situation. The large number of young doctors in the Link study who were altering their career plans is disquieting; it suggests that cities known for their large AIDS population may have difficulty recruiting adequate numbers of doctors to provide care, even if no doctors overtly refuse to treat AIDS patients. One resident told me he specifically chose to go to Los Angeles rather than San Francisco to do his internal medicine residency because San Francisco has "too much AIDS". Clinicians at various San Francisco hospitals feel that this trend away from San

Francisco is leveling off as young doctors realize that AIDS is inevitably going to be a part of their practices, and decide that San Francisco is the best place to receive the training to treat AIDS patients. However, as the predominant group with AIDS becomes intravenous drug users, hospitals may begin to have a more difficult time attracting personnel than they did when the predominant population was homosexual men. Many of the homosexual patients with AIDS have been well-educated, upper middle class patients, often from similar backgrounds to the physician's. Physicians see drug abusers as difficult, untrustworthy patients whose self-destructive behavior is next to impossible to stop. Doctors may consciously or unconsciously question whether they should have to risk acquiring a fatal infection to save the life of a self-destructive patient.[25] Thus the shift in the AIDS population from homosexual men to intravenous drug users may cause more physicians to avoid regions with large numbers of AIDS patients.

Another threat to access to care for AIDS patients is the fast dwindling resources for AIDS care. The rapidly growing population of AIDS patients may soon overwhelm the resources available for care. A recent article in the Los Angeles Times reported that the University of California

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[25] Deborah J. Cotton, "The Impact of AIDS on the Medical Care System," Journal of the American Medical Association 260(4):519-523.

system, on which a third of the state's AIDS patients rely, is close to reaching its capacity for AIDS care and has in a few cases been forced to refuse new patients.[26] The outpatient AIDS clinic at the University of California, San Francisco has been closed to new patients one-fourth of the time over the last year. The San Francisco Veterans Administration Hospital is already experiencing staffing constraints in its infectious disease clinic; its resources for AIDS care may be depleted in the near future.

Even in the best case scenario of no compromise in AIDS patients' access to health care, the anxiety engendered within the medical profession by the possibility of occupationally-acquired HIV infection is not likely to dissipate any time soon and deserves to be addressed. Even if no physicians refuse to treat AIDS patients, this pervasive fear is likely to take its toll on both physicians and patients. "Events that threaten people's health and safety exact a toll even if they never happen."[27] If fear is involved in many treatment refusals, then presumably combatting fear will decrease the likelihood of refusals to treat AIDS patients. But even if we anticipated no refusals

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[26] Janny Scott, "Overtaxed UC Hospitals Turning Away AIDS Cases, Legislators Told," Los Angeles Times, 25 February 1989, p. 25, col. 1.

[27] Baruch Fischhoff et al., "Defining Risk," Policy Sciences 17:123-139.

to care for AIDS patients, we should address the fear, paralyzing in some instances, with which some doctors are living and which must compromise both their mental health and the care they give their patients.

PART II: EXPERIENCE WITH HIV TREATMENT AT BAY AREA HOSPITALS

The experience with AIDS in San Francisco may represent a model of what is likely to be the response to AIDS in other parts of the country as AIDS spreads more widely. However, studying physicians' responses to AIDS in San Francisco may be either an overestimate or an underestimate of the problem elsewhere in the country. Studying San Francisco may lead to overestimates of problems of access to care for AIDS patients elsewhere because San Francisco has been so hard-hit by the AIDS epidemic. At the same time, because of the predominance of homosexual men in the AIDS population, San Francisco's medical community may have provided better access to care then will occur in a city in which most of the AIDS population is intravenous drug users. In addition, homosexuality has been more accepted in San Francisco, and thus physicians in San Francisco may be less homophobic than in other cities. While these results may not be generalizable to any wider community, the response of a sample of different Bay Area hospitals will give us some idea of the kinds of problems with physician avoidance of AIDS patients that have occurred in the Bay Area, and hospitals' differing responses to the phenomenon.[28]

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[28] Information about Bay Area hospitals was obtained in interviews with clinicians at each hospital using the interview schedule reproduced in the Appendix.

A. San Francisco General Hospital[29]

San Francisco General Hospital has approximately 400 inpatients at any one time, and has well over 100,000 outpatient visits a year. On the medicine service of 120 beds, 40 are usually occupied by AIDS patients. Over ninety-five percent of these patients are gay men; however, drug abusers make up a much larger percentage of the asymptomatic HIV-infected patients seen at San Francisco General.

In 1983, as AIDS patients began to need treatment in increasing numbers at San Francisco General, the level of anxiety about the risk of transmission of HIV to internists was very high. A number of internists called for the establishment of an "AIDS hospital" somewhere other than San Francisco General. Since 1983, the anxiety level has decreased considerably on the medicine service, and there are no longer calls for the establishment of another center for AIDS treatment. Dr. Cooke attributes this change to a number of factors. First, the treatment of AIDS has become "normalized" at San Francisco General. AIDS treatment is a recognized mission of the medical service, and people no longer seek to get "their old jobs back," but recognize that

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[29] Information about San Francisco General provided by Molly Cooke, M.D., Chair, Ethics Committee, San Francisco General Hospital. Date of interview February 23, 1989.

AIDS care is going to be a part of their job. Secondly, the medicine service makes clear to prospective interns and residents the large amount of AIDS care required of those practicing at the General. Thus the people who choose to do their internship or residency at San Francisco General expect to and are willing to treat AIDS patients. Finally, she believes that greater knowledge about the transmission of the virus has also allayed some fears about treating AIDS patients.

Until very recently, San Francisco General had no policy regarding physicians who refused to treat AIDS patients. In 1983, the chief executive officer of the hospital stated that personnel who reported directly to him would not be allowed to refuse to treat AIDS patients. However, doctors do not directly report to the CEO, and therefore he could not articulate a policy that would apply to doctors. Instead, he did the only thing he was empowered to do, which was to charge each clinical department head with formulating an AIDS treatment policy for his or her department. The chief of medicine required all members of the medical staff to treat AIDS patients. The chief of surgery allowed each division to decide how caring for AIDS patients was to be handled, as long as patient care was not compromised.

In early 1989, in response to a perceived lack of access to medical care for AIDS patients in certain surgical

departments, and in response to the medicine staff's offence at what it perceived were the low standards set for surgeons, the Executive Board of the Medical Staff[30] proposed a hospital bylaws change requiring all doctors to treat HIV-positive patients with problems within the doctor's competence. The bylaws change reads,

> Medical staff members and clinical departments shall be responsible for providing the highest standard of care to all patients at San Francisco General Hospital, regardless of financial, social, or infectious status.[31]

This policy must be approved by the full medical staff in June, 1989; it is expected to be approved easily.

San Francisco General has had some problems with alleged lack of access to care for AIDS patients, testing of patients for HIV without adequate informed consent procedures, and with possible denial of medically indicated treatment to people who are believed to be infected with HIV. In particular, internists have complained that the orthopedics department has denied indicated surgery to a number of people positive for HIV. Overt refusals to treat

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[30] The Executive Board of the Medical Staff is made up of the chiefs of all the large clinical services, and a few other physicians. Various subcommittees concerned with ethics, credentials, and hospital privileges report to the Executive Board. It is the usual policy-making group for physicians in the hospital.

[31] Per John Luce, Chief of the Medical Staff, San Francisco General Hospital. Lisa Riveland, third year student at Boalt Hall School of Law obtained the text of the bylaws change from Dr. Luce. He read the text to her over the telephone; she gave me a transcript.

HIV-positive patients have not occurred, but access to care has become limited.

Though overt refusals have not occurred, some surgical procedures have simply not been done on patients who are HIV-positive. Surgeons have given other medical reasons for not doing a particular surgery; the strength of such reasons has varied with the case. Even when the medical reason that the patient did not get the surgery requested was plausible, fear of HIV was sometimes implicated in the decision not to do the surgery. For instance, an AIDS patient with cryptococcal meningitis, who needed permanent intravenous access for medications, did not receive the indicated surgery to put in the access after the surgeon had agreed to do the surgery. When another doctor asked his reason for not doing the surgery, the surgeon said that patients who got this type of access got septic and died, and cited the experience of a physician at another hospital. When the same doctor asked this surgeon about his experience, his statistics did indicate that some patients who received the operation became septic and died, but his numbers of patients were small, and the operation was not uniformly fatal. The surgeon then revealed that the last time he had put an intravenous access in an AIDS patient, one of his residents had been stuck by a needle. This instance typifies the combination of medical and psychological reasons that may underlie a physician's reluctance to do a

procedure on an HIV-infected patient.

The orthopedics department at San Francisco General tests all patients for HIV infection. Their consent process appears to be poor; patients have gotten an HIV test result and said they never knew they were going to be tested for HIV. The obstetrics department tests all patients with risk factors for HIV; 15% of deliveries at San Francisco General are to HIV-positive mothers. The plastic surgery department and the ENT department have both expressed interest in starting to test all of their patients in the near future.

Proper protective equipment is not always available at San Francisco General, and health care workers must sometimes walk long distances to find a container for used needles, or they cannot find the correct size of gloves. Little monitoring of compliance with CDC guidelines[32] has been done, but Dr. Cooke's informal estimate is that CDC precautions are only followed one-third of the time.

San Francisco General has recently made an effort to improve their follow-up and counseling of health care workers post-exposure to HIV. Previously the follow-up of occupationally exposed workers involved little counseling or support.

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[32] CDC guidelines for infection control require the use of gloves whenever blood exposure can reasonably be expected, and protective eyewear, masks, gowns, and gloves whenever spattering of blood can be anticipated.

B. San Francisco General Hospital--Dr. Lorraine Day, Chief of Orthopedic Surgery[33]

Dr. Day has been the object of much controversy at San Francisco General and speaks out often about the need to balance surgeon's and patient's rights.

Dr. Day believes that though AIDS patients do have the right to receive treatment, the doctor also has the right not to be required to take "suicidal" risks. She says that she has never asked for a risk-free environment, but the risks she is expected to take in treating HIV-infected patients are unreasonable. She does not accept the published figures for AIDS transmission because they are based on a lower prevalence rate of HIV infection in the general population than the prevalence rate of HIV in patients seen at San Francisco General, and because the studies have enrolled primarily internists, not surgeons. She states that 90% of the patients on one orthopedic service at San Francisco General were HIV-positive in one random week in March, 1989. She feels that the risk to surgeons from HIV is much higher than advertised and that many surgeons are going to come down with AIDS in the next few years. She fears so greatly for her life that she does not know if she can return to orthopedic surgery after her

[33] Date of interview with Dr. Lorraine Day, March 7, 1989.

sabbatical ends in October, 1989. She is currently on sabbatical and has done no surgery since October, 1988.

Dr. Day complains that the University of California has been unwilling to test for aerosolized virus in the orthopedic operating room because "they don't want to know the answer." In her own tests, Dr. Day has found that the virus does become aerosolized during surgery and the virus particles penetrate conventional surgical masks. She therefore wears a space suit or special garment including a respirator when she operates on a patient whom she knows to be infected with HIV. She provides this equipment herself for her staff. If she knows a patient is HIV-positive, she also does not allow medical students in the operating room, and tries to decrease traffic through the room as much as possible during the operation.

Dr. Day asks all of her patients to be tested for HIV prior to surgery. If they refuse to be tested she tries to talk them into being tested. If they still refuse, she takes the precautions she would take if she knew the patient was infected. She says that 95% of her patients agree to be tested. She says that it is impossible for her to use her protective equipment on every patient and therefore testing is necessary. She doesn't have enough equipment to use it universally, and the equipment is unwieldy and makes breathing difficult.

Dr. Day also complains that the Center for Disease

Control has stated that certain hazards don't exist on the basis of little factual information. She says that she has asked the CDC whether the AIDS virus is found in sweat; they have told her no, but she says they have no references to back up the claim. She says the CDC recently took urine and saliva off the list of potentially infective fluids in the workplace because there had been no instances of transmission yet from these fluids. She feels this recommendation is misleading, and unnecessarily increases health care workers' risks.

Dr. Day also states that on many occasions the proper tools for decreasing occupational exposure have been unavailable at San Francisco General. Sometimes no gloves of the correct size are available in the operating room, or no splash guards are available. When she asks for these items, the response has sometimes been "they are on back order," or "we don't have any--do it without."

She feels that she has the right as a surgeon to know all medical information about a patient, including HIV status. She feels the surgeon has the right to know HIV status not only for self-protection, but because the incidence of post-operative infections is higher in AIDS patients, and she believes there is some evidence that a post-operative infection in an HIV-positive patient can throw the patient into full-blown AIDS.

She regularly gets tested for HIV, and feels that her

patients have the right to know her HIV status. She says most surgeons do not get tested because they don't want to know their status. She feels this position is morally reprehensible, because these surgeons may put their sexual partners and families at risk if they become HIV-positive and are not tested.

She says she has always feared occupational diseases such as hepatitis B and tuberculosis. She has received the hepatitis B vaccine, and would not operate on a patient with active tuberculosis because of the risk to the anesthesiologist. She questions why HIV should be treated any differently than tuberculosis.

Dr. Day feels that there is no problem with access to care for HIV-infected patients at San Francisco General, though fewer procedures are being done on AIDS patients, with no detriment to the patients. Most of these procedures are done purely for diagnostic purposes.

Dr. Day was part of the discussions on the proposed by-laws change at San Francisco General and supports them because she said that she was led to believe they had a provision exempting the physician from treating an HIV-positive patient if doing so was detrimental to the physician.[34]

Dr. Day has been accused by the hospital quality review

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[34] Such stipulations are not included in the bylaws change as it is now written.

board of refusing to treat HIV-infected patients on three occasions. She feels that all of these cases have been misrepresented. One case involved a man with a recurrent posterior shoulder dislocation related to seizures. He was HIV-positive. She says she refused to do surgery on him not because of his HIV status, but because he did not take his seizure medications, and thus surgery was contraindicated.[35] The second case involved an HIV-positive woman with an infected hip. Dr. Day refused to do a total hip replacement because putting a new hip in an infected patient is medically contraindicated.[36] The third case involved an AIDS patient who had tried to kill himself by driving his car off a cliff, and who was brought in with a broken neck. She refused to operate on him, because he was so far gone from AIDS already. He died of AIDS three days later. The quality review board cited these three cases as instances of refusal to treat based upon HIV status. Dr. Day says that when she explained her reasons for her refusal to the board, they agreed with her position, but nevertheless accused her of refusing to treat on the basis of HIV-status.

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[35] An orthopedist at another hospital confirmed that these were good medical reasons for refusing to do the surgery. He was not told the identity of the surgeon in question, nor the fact that the patient was HIV-positive.

[36] Medical literature supports this position.

C. San Francisco Veterans Administration Hospital [37]

The San Francisco Veterans Administration Hospital has 290 active inpatient beds and approximately 120,000 outpatient visits per year. Eight to ten inpatients at any one time have AIDS. Three hundred and fifty patients with HIV are being followed as outpatients. Twenty-five percent of these patients have AIDS, 50% have ARC and 25% are asymptomatic. The San Francisco V.A. takes care of six to seven percent of the AIDS patients in San Francisco. Over 90% of those infected with HIV are gay men, but larger numbers of asymptomatic HIV-infected people are drug users. The V.A. also takes care of two to three times the number of patients with transfusion-associated AIDS as other hospitals in San Francisco, though the absolute number of patients in this category is small. In the last year, the infectious disease clinic at the San Francisco V.A. has seen a doubling of the patients with AIDS, a three- to fourfold increase in the number of patients with ARC, and a five- to sixfold increase in the number of asymptomatic HIV-infected individuals. Dr. Jensen attributes the precipitous rise in asymptomatic HIV-positive patients in large part to the increasing number of people who are getting tested for HIV.

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[37] Information provided by Dr. Peter Jensen, Assistant Chief of Infectious Diseases, Chief of Infectious Disease Clinic, Veterans Administration Hospital, San Francisco. Date of interview March 17, 1989.

Dr. Jensen feels that fear of HIV contagion at the V.A. is not very high, but is highest in older physicians who have had AIDS care "dumped upon them," and among surgeons. He has noticed a lessening in the stridency with which some doctors have voiced their wish not to care for AIDS patients, but he doesn't know whether these doctors have really changed their minds about treating AIDS patients. He attributes the lessening in tension in part to the fairly new policy of allowing physicians to test patients for HIV providing strict protocols are followed, and the wider circulation of information about infection control within the hospital community.

Dr. Jensen believes that the assumption implicit in all policies regarding patient care at the San Francisco V.A. is that all patients will be taken care of regardless of infectious status. However, this assumption does not exist as a separate policy as such. The hospital has felt no need to have such a specific policy.

The infection control department, in particular Dr. Jensen, has been responsible for devising policies regarding AIDS treatment. Though general federal guidelines apply to Veteran Administration hospitals, most working policies are devised by the clinical groups most engaged in the area at issue. Thus Dr. Jensen does not think that the development of AIDS policies in this instance by the infectious disease clinicians is a different method of developing policy than

is usually followed in the hospital. After the infectious disease specialists' policies circulate throughout the hospital for comment, the Executive Board must approve them. All Veterans Administration hospitals are autonomous in their policy-making.

The Chief of Staff of the V.A. is empowered to fire an individual who refuses to treat an AIDS patient. One such firing has occurred. A dentist was fired for refusing to treat an AIDS patient approximately 3 years ago. There was little support among the staff for the dentist. Dr. Jensen believes that any doctor who is emotionally incapable of treating an AIDS patient will be "reassigned"; i.e. denied privileges at the V.A.

Dr. Jensen feels that access to care for AIDS patients at the V.A. is adequate at the present time, but is likely to become compromised by financial and staffing constraints in the near future. Because of the number of physicians on staff who devote almost all of their time to research, there may soon be an inadequate number of clinicians to treat HIV-infected patients. The number of patients with HIV will soon outstrip resources and staffing. In the last six to eight months, the V.A. has already experienced staffing constraints.

The V.A. provides adequate safety equipment and infection control education. Dr. Jensen estimates that compliance with CDC infection control guidelines is very

high. The V.A. provides follow-up post-occupational HIV exposure. Some counseling is involved in this follow-up.

D. Peralta and Samuel Merritt Hospitals[38]

Peralta Hospital has 80 beds and had 4027 inpatient admissions last year. Merritt Hospital has 200 beds and approximately 12,000 admissions last year. On average, six of the eighty beds at Peralta are occupied by AIDS patients at any one time. These patients are primarily homosexual men, and are covered by insurance.

Ms. Stoll feels that fear of transmission of HIV infection occupationally was prevalent at Peralta five years ago, but has diminished to a low level at present. She feels that nurses project a more obviously caring attitude towards AIDS patients now; she does not know about doctors' attitudes towards AIDS patients, but hears no discussion of fear among doctors. She has heard of no refusals to treat AIDS patients at Merritt or Peralta in the last 5 years, though some doctors expressed hesitation about treating AIDS patients 5 years ago. Merritt and Peralta have an AIDS clinic. She feels that no inappropriate referrals to this

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[38] Information about Merritt and Peralta Hospitals provided by Pat Stroll, R.N., Infection Control Coordinator for Merritt and Peralta hospitals. Date of interview, May 3, 1989. Merritt and Peralta Hospitals are private hospitals located in Oakland, California.

clinic occur from doctors trying to shirk treating AIDS patients.

Peralta and Merritt Hospitals have no explicit policy governing treatment of AIDS patients. The mission statement of the hospitals states that they will serve all patients, and the Executive Committee of the Medical Staff has felt no need to adopt a more explicit policy.

Ms. Stoll feels that AIDS patients have adequate access to care at Merritt and Peralta hospitals at the present time, and though she feels that inadequate resources throughout the country will compromise AIDS care, she sees no future compromise in access to care for AIDS patients at Merritt and Peralta for financial reasons.

Peralta and Merritt have extensive education programs about infection control procedures, and Ms. Stoll believes that compliance with CDC precautions is very high. The hospital recently passed an OSHA inspection in which hospital workers were asked about whether they had adequate education about and equipment for infection control, and were observed working. OSHA found that employees complied with infection control procedures and were confident that the hospital provided as much protection against occupational infections as possible. Any Merritt or Peralta employee exposed to HIV occupationally is offered counseling, anonymous testing at the time of exposure, and at 3 months, 6 months and 1 year post-exposure.

In general, Ms. Stoll feels that Peralta and Merritt Hospitals have been effective in educating their workers, and in conveying a sense of caring about the health of their workers. She believes the quality of AIDS care at her institutions is very high, and refusals to provide care are not a problem in these hospitals.

E. Alta Bates-Herrick Hospital[39]

Dr. Micco feels that fear of contracting AIDS occupationally is not widespread at Alta Bates, but that it is fairly prevalent in certain departments.[40]

Alta Bates is now in the process of developing a policy regarding treatment of AIDS patients. This process began in 1988 when some physicians complained that one physician at Alta Bates had failed to provide appropriate treatment to an HIV-positive patient, and suggested an Ethics Committee meeting to discuss the case. When the meeting occurred, discussion was heated, with some physicians backing the physician in question, and others accusing him of acting inappropriately. Soon after this Ethics Committee meeting,

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[39] Information about Alta Bates-Herrick Hospital provided by Guy Micco, M.D., Chair, Ethics Committee, and Member, AIDS Oversight Committee, Alta Bates Hospital. Date of interview, May 5, 1989. Alta Bates-Herrick Hospital is a private hospital located in Berkeley.

[40] Dr. Micco did not want me to identify the particular departments.

the AIDS Oversight Committee was formed by the Executive Board of the Medical Staff as the policy-making body for all issues having to do with AIDS treatment. This committee reports to the Executive Board.

The AIDS Oversight Committee drafted a proposed hospital bylaws change that reads,

> It is the responsibility of each Medical Staff Department to insure access to appropriate medical care for all patients of Alta Bates-Herrick Hospital.

This policy was passed unanimously by the AIDS Oversight Committee and sent to the Executive Board in March, 1989. The Executive Board is currently circulating the policy to the clinical departments for comment. Dr. Micco senses that a large number of doctors do not support the policy, for a number of reasons. Some doctors do not want the primary responsibility for providing access to care to rest with the department, because they are afraid that other doctors will "dump" their AIDS patients on them. They thus want the responsibility to treat to rest with each physician. Others think the hospital should not have a policy that requires department heads to be the authorities in assuring access to care. Some doctors think that the policy should impose a duty to treat AIDS patients on each physician, and that the present policy is not a strong enough statement of Alta Bates' commitment to providing access to care for AIDS patients. Others think providing care to AIDS patients is a personal decision that each physician should be allowed to

make without interference from the hospital. Thus it is unclear whether this bylaws change will be approved by the Executive Board of the Medical Staff. If the bylaws change does pass, there has been no discussion of attaching any sanctions to the policy for failing to assure access to care. Since the obligation rests with each department, it would be difficult for the hospital to enforce sanctions against an entire department. Therefore, the nature of the sanctions, if any are developed at all, is unclear.

Dr. Micco has heard reports of denials of care to HIV-infected patients, or of the rendering of inappropriate care to AIDS patients, but has observed no refusals himself. Some reports of inappropriate care have been contested, with other members of the department backing the medical judgement of the physician in question. In one apparent refusal, a physician refused to do mouth-to-mouth resuscitation on an AIDS patient, and required a nurse to do it in his place. In one clinical department, every physician is unwilling to treat AIDS patients, so the department is trying to contract with an outside physician to provide care to AIDS patients. They have apparently not been successful in finding a physician willing to take on this responsibility to date. Thus Alta Bates seems to have some problems with physicians avoiding care of AIDS patients, but Dr. Micco feels that generally access to care for AIDS patients at Alta Bates is adequate. However, he

thinks that access to care for AIDS patients has the potential to become a big problem at Alta Bates in the future because of physicians avoiding treating AIDS patients.

F. Kaiser-Permanente Medical Center, San Francisco[41]

Kaiser-Permanente Medical Center in San Francisco has approximately 360 inpatient beds of which fifteen are filled with AIDS patients at any one time. Kaiser does not have a written policy specifically regarding care of AIDS patients, but Kaiser's policy is understood by the staff to state that every doctor must treat his or her fair share of AIDS patients. However, in actuality, some physicians at Kaiser are caring for far more AIDS patients than other physicians at Kaiser. One of my sources estimates that approximately 40% to 50% of physicians at Kaiser are treating AIDS patients. The rest do not treat significant numbers of AIDS patients, either because they are subspecialists who do not have any additional appointment time available to see more

[41] The doctors who provided the information on Kaiser-Permanente Medical Center spoke to me on the condition that they not be identified.

patients,[42] or because of "bad chemistry" between physicians and AIDS patients. My sources believed that a large number of physicians at Kaiser project a negative attitude towards AIDS patients, and therefore AIDS patients do not return to these physicians for future appointments. However, my sources did not believe that any compromise in access to care for AIDS patients has occurred at Kaiser to date.

[42] Kaiser expects subspecialists to be the "primary physician" for a certain number of patients, including AIDS patients. However, if their practice is filled with patients in need of their subspecialty skills, they have little appointment time to act as a primary physician for other patients, including AIDS patients.

PART III: DEFINING THE RISK OF OCCUPATIONALLY-ACQUIRED HIV INFECTION

The ways in which the risk of HIV infection is defined socially, and the ways in which it is perceived individually contribute to people's views about the right of physicians to refuse to treat AIDS patients. If the disease is defined as an "excessive risk" to physicians, then physician refusals to treat HIV-infected patients become easier to justify as reasonable. If the risk is "acceptable," physician refusals are easier to characterize as unethical. How do we define "acceptable" and "excessive" risk? And why do many physicians perceive as so overwhelming a risk of dying that is lower than the risk of dying from some daily activities, and lower then their risk of dying from occupationally-acquired hepatitis (if they have not received the hepatitis B vaccine)?

The next section of this paper discusses definitions and perceptions of risk which determine why some doctors find the risk of AIDS extremely worrisome, and the assumptions involved in focusing the debate about physicians' duties to HIV-infected patients around questions of "acceptable" versus "excessive" risk. I find that trying to distinguish between "acceptable" and "excessive" risk is ultimately not very useful in the debate about whether physicians have an obligation to treat AIDS patients, since society can never derive an objective "number" for acceptable risk. In addition, psychometric research shows

that physicians' responses to the risk of contracting HIV occupationally should not be characterized simply as "hysterical," and cannot therefore be easily dismissed. They are understandable fears that are not likely to disappear when doctors are given more education about occupational transmission of the AIDS virus. Thus the position that doctors must treat AIDS patients simply because their fears are groundless, and their risk is "acceptable" is not an adequate response to physicians who avoid treating HIV-infected patients.

A. "Objective" Risk of Transmission of the AIDS Virus in the Medical Care Setting

Recent estimates in the New England Journal of Medicine have put the risk of infection with HIV after mucous membrane exposure or parenteral inoculation of infected blood, fluids, or secretions at a maximum rate of seroconversion of 1 per 200 exposures.[43] The Center for Disease Control estimates the risk of becoming seropositive after a single HIV-contaminated needlestick as 1 percent or less.[44] The American College of Physicians estimates the

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[43] Ezekiel J. Emanuel, "Do Physicians Have an Obligation to Treat Patients with AIDS?" New England Journal of Medicine 318(25): 1686.

[44] Ibid. p. 1688.

risk at .5% per needlestick exposure.[45] Other studies put the risk between 3/10,000 and 90/10,000 per parenteral exposures.[46] Nine prospective studies of 3500 occupationally exposed health care workers have documented four seroconversions among this group, as of November 1987.[47] Thus the risk of occupational infection with HIV seems to be "objectively" small, but clearly not zero. No physician can assume herself to be completely free of risk of contracting AIDS because of her occupation. In addition, since AIDS is such a new disease, our knowledge about the disease and its routes of transmission is evolving. Just because one route of exposure has not resulted in any seroconversions to date does not mean that we can conclude that there is no risk of infection by this route. The studies of exposed health care workers on which these estimates are based contained very few surgeons.[48] Thus in the future it is possible that more physicians will acquire

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[45] Health and Public Policy Committee, American College of Physicians, "The Acquired Immunodeficiency Syndrome and Infection with the Human Immunodeficiency Virus," Annals of Internal Medicine 108(1988):460-469.

[46] Michael D. Hagen et al., "Routine Preoperative Screening for HIV," Journal of the American Medical Association 259(9):1357-1359.

[47] Julie Gerberding, "Occupational Infection: A Worry That Won't Go Away," AIDSFILE, November 1987. On file with Dr. Guy Micco.

[48] Trisha Barrett, R.N., Infection Control Coordinator, Alta Bates Hospital; Lorraine Day, M.D., Chief of Orthopedic Surgery, San Francisco General Hospital.

HIV at a faster rate than they have in the past.

Some health care workers probably have a greater risk of seroconversion than others. Those who perform invasive procedures seem logically to have a greater risk of infection because they are exposed to large quantities of blood. Surgeons are exposed to blood and use sharp instruments; they are therefore at greater risk of cutting themselves in a blood-contaminated environment. In a specialty such as orthopedic surgery, the surgeon cannot avoid some occupational injuries; these surgeons are using saws and other sharp instruments, and sharp bone shards often pierce their protective gloves. Estimates of occupational exposure to surgeons have been a good deal higher than the estimates of risks to other physicians, though surgeons have not become infected more frequently than other health care workers to date. One recent estimate assumed 40 needlesticks per year for emergency department surgeons; according to this estimate, these individuals have a 2% annual risk of seroconversion (40 sticks with 4.6% infected with HIV and a 1% risk of HIV infection from a stick).[49] Dr. Day, head of orthopedics at San Francisco General estimates her 5 year cumulative risk of seroconversion at 49% (40 sticks, 33% infected with HIV, 1%

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[49] Ezekiel J. Emanuel, "Do Physicians Have an Obligation to Treat Patients With AIDS?" New England Journal of Medicine 318(25):1686-1690.

risk with each puncture).[50] Hagen estimated that significant skin puncture occurs once every 40 surgical cases. Since the average surgeon performs about 360 operations a year, the average surgeon sustains approximately 9 needlesticks a year. Thus different physicians may be exposed to different levels of risk, but the magnitude of the difference is debated. Studies of health care workers who have sustained occupational exposures to HIV follow a group of health care workers with very different daily exposures to blood and sharp instruments. Thus the results of these studies may not accurately reflect the risk to a particular surgeon.

To add to the confusion for a physician trying to compute her risk of seroconversion, a recent article in the New England Journal of Medicine suggests that the seroprevalence rate of HIV among individuals presenting to an inner city emergency room may be higher than previously thought.[51] Kelen found that 4% of consecutive adult patients presenting to an inner city emergency room had unrecognized HIV infection. Those who presented with penetrating trauma had a seroprevalence rate of 13.6%. Thus

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[50] Ibid. p. 1688. However, her methods of computing her risk have recently been brought into question. See Michael D. Hagen et al., "Routine Preoperative Screening for HIV," Journal of the American Medical Association 259(9):1357-1359.

[51] Gabor D. Kelen et al., "Unrecognized Human Immunodeficiency Virus Infection in Emergency Department Patients," New England Journal of Medicine 318(25):1645-1650.

physicians may be exposed to more HIV-infected patients than has been previously postulated. Patients who presented a high likelihood of blood exposure to the physician (e.g. those with penetrating trauma) had a particularly high rate of seropositivity. Without testing patients, physicians cannot identify patients with HIV infection until they become symptomatic. They usually do not know how many of their patients are HIV-positive and therefore they cannot be sure of their risk of seroconversion.

All of the estimates of risk are "low." However, "low" is defined in relation to the risk of something else. Thus the risk of contracting AIDS is lower than the risk of contracting hepatitis B (prior to development of an effective vaccine, which now exists), but it isn't lower than the risk of being electrocuted by electrical equipment in the operating room, or dying of radiation-related diseases from performing diagnostic radiography. In addition, these "low" estimates of risks vary many-fold. Are the estimates of the risk of occupational seroconversion all so low that the difference between an estimate of 1/100 chance of seroconversion per exposure, and an estimate of 3/10,000 chance of seroconversion after exposure doesn't really matter? Or are we willing to accept a risk of 3/10,000 for health care workers, but not a risk of 1/100? Is 1/100 a "vanishingly small" risk? Is 3/10,000?

B. Defining Risk and Its Acceptability

Scientific estimates of risk are often referred to as "objective" methods of risk assessment, and other "non-expert" assessments are referred to as "subjective."[52] At the outset, we must realize that defining risk and its acceptability, by whatever means, is an inherently political process. "Values and uncertainties are an integral part of every acceptable-risk problem...as a result, there is no single all-purpose number that expresses 'acceptable' risk for a society. Not only does each approach fail to give a definitive answer, but it is predisposed to representing particular interests and recommending particular solutions. Hence, choice of a method is a political decision with a distinct message about who should rule and what should matter."[53]

The search for an "objective method" of determining risk denies the inevitable political dimensions of such a determination and may blind those searching for the definition to their own value-laden assumptions.[54]

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[52] Baruch Fischhoff et al., "Defining Risk," Policy Sciences 17:123-139.

[53] Baruch Fischhoff, et al., "Approaches to Acceptable Risk: A Critical Guide" (Prepared for Oak Ridge National Laboratory and U.S. Nuclear Regulatory Commission, 1980), pp. ii-iii. as quoted in Mary Douglas and Aaron Wildavsky, Risk and Culture (Berkeley: University of California Press, 1982).

[54] Ibid.

"Developing a definition of risk requires a variety of explicit value judgments. Choosing to express risk in a numerical index may itself make a statement of values."[55] Characterizing occupational risk of AIDS as "low" makes it easier for society to assume that it is acceptable for health care workers to assume the risk associated with occupational exposure to HIV, as long as it remains "low". Certainly society has an interest in seeing that physicians keep treating AIDS patients. Does this fact have any impact on how the society characterizes the occupational risk of HIV infection? On the other hand, Mary Douglas argues that "public moral judgments powerfully advertise certain risks. The well-advertised risk generally turns out to be connected with legitimating moral principles."[56] Perhaps advertising the risks of AIDS to "bystanders" reenforces the retributive notion of the disease. It suggests that doctors should not get too near the "guilty victims" of the disease lest they are accidentally touched by the scourge. Emphasizing health care workers' risks of "accidentally" acquiring the AIDS virus implies that other victims of the disease did not get it "accidentally" e.g. there was a "reason" that they got the disease. Thus the emphasis on doctors' risks of

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[55] Baruch Fischoff, et al., "Defining Risk", Policy Sciences 17:123-139.

[56] Mary Douglas, Risk Acceptability According to the Social Sciences (New York: Russell Sage Foundation, 1985), 60.

acquiring HIV occupationally may arise in part from the pervasive social stigmatization of homosexuals and drug users as somehow being responsible for their disease, as opposed to the "innocent" victims who "accidentally" got the disease.

In addition, the "acceptability" of a risk is also defined in part by the social class of people who are exposed to it. Thus the risk of HIV infection to doctors and nurses gets more emphasis in the literature than the risk of HIV infection to housekeeping staff, who are in fact also at risk of occupational exposure to HIV via needlesticks.

Once the decision is made to decide on a level of "acceptable" risk, it is clear that someone thinks the proposed activity is dangerous. Hazard is usually treated as an independent variable and people's perceptions of it as dependent. However, the construction of a hazard is subject to social forces.[57] Physician precautions when working with HIV-infected patients have gotten much more emphasis than universal precautions for hepatitis patients did in the past. Occupational HIV infection has been defined as a danger. In addition, the way the problem is defined may affect which of our basic values we believe to be relevant to the situation. Is the problem of physician avoidance of

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[57] Mary Douglas, Risk Acceptability According to the Social Sciences (New York: Russell Sage Foundation, 1985), 26.

AIDS patients that of stopping physicians from unethically refusing to treat sick patients, or is it that of minimizing the exposure of health care workers to a deadly disease?

Discussions of occupational risks of HIV infection often suggest that since the risk of infection is "low", it is "acceptable." Some authors suggest that the risk for most health care workers is "acceptable," but for some the risk may become "unacceptable."[58] These arguments assume that there is some absolute number "out there" such that risks of HIV transmission below that number would be acceptable, and risks above that number would be unacceptable. As we saw however, the estimates of transmission of AIDS vary 100-fold. There are also quite different risks of seroconversion for various physicians--yet all these different risks may be "acceptable". In addition, some doctors perceive their risk of HIV infection as higher than that estimated scientifically. Do we give weight to this perception in determining the "acceptable" level of risk from HIV? Should the definition of an "acceptable" risk of HIV transmission be a social or individual one?

The line between acceptable and excessive risk is not clear and depends on socially determined ideas of reasonable

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[58] Ezekiel J. Emanuel, "Do Physicians Have an Obligation to Treat Patients with AIDS?" New England Journal of Medicine 318(25):1686-1690.

risk. What might have been a reasonable risk for a physician working in London during the plague, when everyone in the society was at high risk of contracting the disease, might be quite different than the level of risk our society would find acceptable today. We live in the age of antibiotics where people do not expect to die of infectious diseases. Doctors especially are used to treating formerly deadly diseases, and they do not expect anyone, much less themselves, to die of an infectious disease. Doctors may often feel that if they were in another profession, their risk of AIDS would be zero; therefore any risk above zero is too much. In addition, many doctors feel that AIDS "was not part of the bargain" when they entered medicine. It has been "dumped upon them" and they do not feel that they should have to accept any risk of HIV infection.

People do not "accept risks." "The act of adopting an option does not in and of itself mean that its attendant risks are acceptable in any absolute sense."[59] People accept an option that entails a certain risk among its consequences. The option must be evaluated on all its features, not just its risk. Thus the acceptability of the risk of HIV infection to the doctor depends upon the benefit of the procedure to the patient, and how the physician weighs the benefits of practicing medicine. Deciding which

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[59] Baruch Fischhoff et al. Acceptable Risk (Cambridge: Cambridge University Press, 1981), 3.

option is the most attractive is situation specific--there are no options that will be acceptable in every case.

Changes in technology, errors in analysis which are discovered later, and changing social values may all lead to one option becoming more attractive over time. Thus if we develop technology that limits the number of needlesticks any one physician should get, the level of risk which the profession or society considers "acceptable" might also decrease. "Accidental" exposures to contaminated blood would no longer be considered "normal". If epidemiologists find that surgeons have a greatly increased risk of seroconversion over other physicians, society will have to reevaluate what it considers to be an acceptable risk for surgeons to take, and might enable surgeons to take previously forbidden measures to lower their risk. For instance, if surgeons are at an increased risk of seroconversion, routine preoperative testing of all non-emergency surgery patients might become an accepted risk-reducing measure.

There is no magic level of risk which society can legislate as the "correct" amount of risk an individual health care worker should be obligated to assume in treating HIV-positive patients. The risk the physician accepts is contingent upon the benefit to the patient of a particular procedure, the other obligations of the physician, and the level of risk that her colleagues are accepting. In

addition, the significance of one risk for any one individual may vary with the amount of risk in her personal life. For a healthy young person with no bad habits living next to Three Mile Island, the risk of radiation exposure from the plant may be the most significant risk she faces.[60] Occupational exposure to HIV infection may be the most significant risk of death a young, healthy doctor faces, but would not be the most significant risk in the life of a doctor who does rock-climbing in her spare time, or who is sixty years old and smokes three packs of cigarettes a day. Thus, the risk of HIV infection in relation to the individual's risk from other daily activities is "lower" for the smoker than the non-smoker. Can society then define the occupational risk as more "acceptable" for the smoker than for the non-smoker or for the rock-climber than the non-rock-climber?

Efforts to garner a consensus around some number representing the "acceptable" risk to health care workers are doomed to failure. Thus we must abandon these efforts to convert doctors to the point of view according to which their risk is characterized as "low" and therefore "acceptable." Equally valid methods of calculating "acceptable risk" may lead to vastly different results.

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[60] Raphael Kasper, "Perceptions of Risk and Their Effects on Decision Making." In Societal Risk Assessment: How Safe is Safe Enough? (New York: Plenum Press, 1980), 71.

C. Individual and Social Perceptions of Risk

Illness and contagion have social definitions. The definition of a disease affects the way the risk of getting that disease is defined. The definition of AIDS as the modern "plague" colors all reaction to it. Plague has often been used as a metaphor for the largest of collective catastrophes, as well as a term for frightening diseases.[61] Diseases that transform and disfigure the body such as leprosy or syphilis, in addition to being fatal seem to be particularly likely to be labeled "plagues".[62] "From classic fiction to the latest journalism, the standard plague story is of inexorability, inescapability. The unprepared are taken by surprise; those observing the recommended precautions are struck down as well."[63] Clearly these metaphors influence doctors' perceptions of AIDS just as they do the larger community. AIDS is one of a succession of "plagues" in which the disease is seen as having a retributive purpose.[64] It strikes "innocent victims" as well as "the guilty". It is seen by many as punishment

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[61] Susan Sontag, "AIDS and its Metaphors," The New York Review of Books, 27 October 1988, p. 89-99.

[62] Ibid. p. 90.

[63] Ibid. p. 90.

[64] Ibid. p. 89.

inflicted upon a particular community--a risk group, "that neutral-sounding bureaucratic category which also revives the archaic idea of a tainted community that illness has judged."[65] These are the "guilty" victims, but the inexorable disease also will mow down the innocents: unborn babes, blood transfusion recipients, health care workers. "Such is the potency and efficacy of the plague metaphor: it allows a disease to be regarded both as something incurred by vulnerable "others" and as (potentially) everyone's disease."[66] Once AIDS is defined as an inexorable, relentless plague, mowing down the protected and unprotected alike, individuals perceive their risk of the disease as higher.

Another social factor which clearly contributes to the perception of risk from AIDS is the link between AIDS and sexuality. Most people still view AIDS as primarily transmitted via homosexual sex. Though the virus is also transmitted transplacentally, through heterosexual intercourse, and via blood, it is linked quite clearly in the public eye with being a homosexual male. In informal interviews with police officers, the interviewer gave the officers a choice between a high probability of being shot

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[65] Ibid. p. 89.

[66] Ibid. p. 90.

and a low probability of being infected with AIDS.[67] Most officers preferred, even at very high probabilities, to take the risk of being shot over any risk of getting AIDS. They articulate the reason for this seemingly irrational choice as arising from the fact that if they are shot in the line of duty they will be viewed as heroes whereas if they are infected with HIV, their colleagues will only say "I always knew he was a little 'funny'." Doctors too cannot look forward to being hailed as heroes or heroines if they contract HIV in the course of their work. Their associates may wonder whether they indeed did contract the infection at work, and are not likely to congratulate them for their courage in treating AIDS patients.

Certainly the metaphors surrounding AIDS as the "modern plague" contribute to people's perceptions of their risk of contracting the disease. But even if the disease were less value-charged, it is unlikely that fear of AIDS would disappear. Much has been written about the fears "unsupported by medical evidence" surrounding the transmission of AIDS. The clear implication in these statements is that fear of AIDS stems only from ignorance. Psychometric research suggests that such a simple

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[67] Private communication, Jolanda Janczewski, Biosafety Officer and Health Educator, NCI--Frederick Cancer Research Facility.

Interview, February 23, 1989 with Molly Cooke, M.D., Chair, Ethics Committee, San Francisco General Hospital.

explanation is not accurate.

People perceive risks in predictable ways. Their methods of risk perception may include important factors that a "rational" risk assessment would not include.[68] When "experts" judge risk, their estimates correlate closely with annual fatality rates. Laypersons judgments of risk are related more to other factors than simply to the annual number of fatalities expected. Slovic found that some of the most important of these characteristics of a risky activity are: its catastrophic potential, the familiarity of the risky situation, personal control over the risk, and an unknown potential for disaster in the risky situation.

Slovic uses factor-analytic representations with two axes to quantify perceptions of risk. The horizontal axis is labeled "dread risk"; it is defined at its high end by a perceived lack of control over the event, feelings of dread at the thought of the possible outcome of the event, the catastrophic potential of the event, fatal consequences, and inequitable distribution of risks and benefits. Nuclear weapons and nuclear power score very high on this scale. Measuring AIDS risk on this scale, AIDS too would score very high. Transmission of AIDS in the health care setting is perceived to be uncontrollable; transmission is "accidental," that is, the incident that led to transmission

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[68] Paul Slovic,"Perception of Risk," Science 236:280-285.

could not have been foreseen. Clearly, the probability of many of the accidents involving exposure to HIV could be decreased by using protective equipment or clothing. Nevertheless, doctors may feel that it is only a matter of time until they accidentally lose their concentration and stick themselves with a needle; the protective equipment they need is not available in an emergency; their glove happens to have a hole in it; or the glass tube they are filling with blood shatters.

HIV infection is clearly viewed with a great deal of dread, possibly particularly by doctors. Doctors are well aware of the sequelae that follow a diagnosis of AIDS. They have seen young people become demented, die on respirators, become disfigured by skin lesions. The terrible toll taken on people who may be the same age or younger than the doctor may make the prospective death seem that much more horrifying.

AIDS is a 100% fatal disease. It is in that sense individually catastrophic. It is also catastrophic for the social relationships of the person diagnosed with AIDS. A person diagnosed with HIV infection is profoundly stigmatized; she may lose her housing, her job, and her family and friends. Adding to the dread of the ultimately fatal outcome of the disease is the dread of dying alone and uncared for. All of these factors contribute to a very high score on the horizontal axis of the factor-analytic

representation.

Slovic's vertical axis of the factor-analytic representation is labeled "unknown risk." It is defined at its high end by hazards judged to be unknown, new, unobservable, and delayed in their manifestation of harm. Potential chemical carcinogens score very highly on this axis. Measuring AIDS on the vertical axis of the factor-analytic representation, the disease again scores very high. AIDS is a new disease; every year the estimates of the percentage of HIV-infected people who will go on to develop AIDS and ultimately die have been revised upwards until they are now close to 100%. Many doctors question how much we really do know about a disease that has only been recognized for seven or eight years. They often echo the sentiment of Dr. Schecter at San Francisco General, "The important point is we know very, very little as far as I'm concerned about how this virus is actually transmitted."[69]

HIV-infected people do not know when or how the disease will manifest itself. The disease may appear in the next few months, or it may take years to manifest. Though the ultimate fatal outcome is all but a certainty, patients do not know how much time they have left to live, or which of the many opportunistic infections will kill them. Thus even after being diagnosed with HIV a person must live with

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[69]Carol Pogash,"Bad Blood," San Francisco Chronicle, 15 January 1989, Image Magazine section.

considerable uncertainty.

Thus on Slovic's scale for quantifying risk perception, AIDS scores high on both factors: dread and unknown potential. Should we then be surprised that people perceive it as a high risk? We would expect, using Slovic's method, that it would be likely to be perceived as a great risk, even in the face of evidence showing low transmission rates. Nuclear power is perceived as a great threat by many people when in fact the expert assessments of the risks from nuclear power are extremely small. The same factors are likely to be at work in perceptions of risk from nuclear power and from AIDS.

Psychometric research has also revealed that the perceived seriousness of one unfortunate event is determined in part by what the event "signals".[70] Thus, an accident which takes many lives such as a train wreck, which occurs within a familiar and well-understood system may create little social disturbance. On the other hand, an accident which takes few or no lives, but which occurs in a poorly understood, new system (e.g. a nuclear power accident such as that at Three Mile Island) may have immense social consequences. Thus three health care workers becoming infected with HIV by a route other than a needlestick (as occurred in 1987) produced tremendous panic within the

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[70] Ibid.

medical profession because it suggested that the virus might have other unknown routes of transmission and showed there were limits on what we knew about the transmission of the virus.

Finally, psychometric research has found that voluntariness of exposure to a hazard is the key determinant of risk acceptance.[71] A hazard imposed upon an individual by the society is less tolerable than a risk undertaken voluntarily by the individual. Starr found that the public was willing to accept "voluntary" risks a thousand times greater than "involuntary" risks.[72] If the voluntariness of the risk is indeed a component of risk perception, it should make us wary of requiring physicians to treat AIDS patients by legislation or by rules made by authority figures. Requiring the activity may in fact increase the perception of working with HIV-infected patients as a risky enterprise, and lead to greater resistance to treating these patients.

Discussions of physicians' fears of AIDS patients tend to focus on the "irrationality" of such fears, and suggest that a little more education might overcome such irrational notions and enable people to think rationally. The major

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[71] Chauncey Starr, "Social Benefit versus Technological Risk," Science 165:1232-1238.

[72] Ibid. However, Slovic has questioned whether "voluntariness" is in fact the key mediator of risk perception, and suggests that it may appear so because of the overlap between involuntary and dreaded, unfamiliar activities. See Paul Slovic, "Perception of Risk," Science 236:280-285.

theory of decision-making under risk is the expected utility model. This model postulates that a rational decision-maker will prefer the choice that offers the highest expected utility. It also postulates that the rational decision-maker will weight uncertain outcomes by their probability. Again, however, psychological research suggests that people do not use the expected utility model in making decisions about risk. Tversky and Kahneman found that people systematically violate the requirements of consistency (a seeming requirement for "rational" thought) depending on the formulation of the decision problem.[73] People conceive of problems as being different, when in fact they are the same, depending on the way in which the problem is phrased. They reverse their preferences if the choice is phrased as a loss or a gain.

Kahneman and Tversky also found that people do not weight uncertain outcomes by the probability. Low probabilities are overweighted and moderate to high probabilities are underweighted. Thus individuals underestimate their chances of being involved in a fatal car accident, but overestimate their chances of contracting HIV occupationally.

Finally, Tversky and Kahneman found that individuals faced with a two-stage problem in which the two stages are

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[73] Amos Tversky and Daniel Kahneman, "The Framing of Decisions and the Psychology of Choice," Science 211:453-458.

linked make their decisions as if the second stage has already been reached, even if the probability of getting past the first stage is very low.[74] Thus people pay attention only to the probability associated with the second stage decision. HIV transmission presents just such a two-stage problem, and some physicians' responses to it illustrate the above effects. Contracting AIDS involves two steps: the probability of transmission of the virus, and the chance of dying from AIDS once one has the virus. The probability of transmission by any one exposure to infected blood is approximately one percent or lower; the probability of dying from AIDS after contracting the virus approaches 100%. If people treat the two-stage problem as simply the problem of the second stage, it is not surprising that they fear contracting HIV. The certainty of death in the second stage overshadows the small risk of transmission in the first stage of the problem.

Physicians' risk from hepatitis B is an analogous two-step problem. Hepatitis risk is perceived as low by many physicians, though it in fact poses a greater threat to the lives of health care workers than does HIV infection. [75] Many health care workers have not gotten the safe and

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[74] Ibid.

[75] 300 health care workers died from hepatitis B infection last year. Per Trisha Barrett, R.N., Infection Control Coordinator, Alta Bates Hospital.

effective hepatitis vaccine that now exists. Acceptance rates for the vaccine are low even after interventions specifically aimed at increasing the acceptance rate.[76] The perceived risk of infection with the virus is the most important factor predicting vaccine acceptance.[77] Thus clearly, physicians perceive their risk of dying from hepatitis as low. Since hepatitis B and HIV infections affect the same risk groups, and are both transmitted by blood products, why is there this differential perception of risk from the two diseases?

The two-stage problem formulation is at work in the differential perception. Let us compare AIDS to hepatitis B using the results of Tversky and Kahneman's research on two-stage decision making. Hepatitis has a probability of transmission of approximately 30% per blood exposure. There is a risk of dying from the disease if one contracts the virus of .3% to 1%.[78] Here the second stage probability is much lower than the first stage probability. The relatively high risk of contracting the hepatitis virus is ignored, and

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[76] Carolyn Clancy et al., "Guiding Individual Decisions: A Randomized, Controlled Trial of Decision Analysis," The American Journal of Medicine 84:283-288.

[77] Ibid.

[78] Henry S. Sacks, et al., "Should the Risk of Acquired Immunodeficiency Syndrome Deter Hepatitis B Vaccination?" Journal of the American Medical Association 252:3375-3377.
R. H. Hamm, "Hepatitis B Among Dental Patients," Journal of the American Medical Association 253:1239-1240.

the low probability of death in the second stage of the decision is stressed, leading to a false sense of security about hepatitis risk. Thus even though the overall risk of dying of hepatitis is higher than AIDS, it is often not perceived as higher.

People use one final method when they analyze risks. When they are asked to judge the relative frequency of particular events, they often make use of what Nisbett calls the "availability heuristic."[79] Their perceptions of the frequency of a particular event are influenced by the "availability" in their consciousness of that event e.g. its "...accessibility in the processes of perception, memory, or construction from imagination."[80] Particularly vivid events are likely to be more accessible in memory and therefore will lead people to overestimate the frequency of these or similar events. Thus the surgeon who is loath to do a particular operation on an AIDS patient, because the last time he did the operation on an HIV-positive patient a member of his housestaff got a needlestick, may be using the availability heuristic. The vivid link in his memory between the needlestick and that particular kind of operation may lead him to overestimate the chance of a

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[79] Richard Nisbett and Lee Ross, Human Inference: Strategies and Shortcomings of Social Judgement (Englewood Cliffs, New Jersey: Prentice-Hall, Inc., 1980), 6.

[80] Ibid. p. 18.

needlestick occurring during that particular operation, and he may be reluctant to perform that operation on an HIV-positive patient while he continues to do other operations on HIV-positive patients.

In addition, the availability heuristic reflects the fact that "for us ordinary mortals, events that do occur are vastly more real and immediate than the corresponding nonoccurences of potential events."[81] Thus the seroconversion of one nurse at San Francisco General hospital engendered far more anxiety than the security engendered by the non-seroconversion of eight hundred others.

These methods of perceiving risk are reproducible in various populations, and thus it is unrealistic to hope that education alone, or calls to "rationality" alone will diminish fears based on effects of this kind. Doctors are not simply "irrational" in fearing AIDS. To accuse doctors of irrational fear is to imply that the fear is not justifiable, and would just go away if doctors had more knowledge. Since we cannot change the "problem formulation" of AIDS--the risk of death will always overshadow the low risk of transmission, our time could be spent more productively in finding other solutions to the problem of fear of HIV transmission than in efforts to help doctors

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[81] Ibid. p. 48.

"think rationally" about their risk from AIDS.

D. How Does the Community Shape Risk Perception?

The most underexplored aspect of risk perception is how it is shaped by different communities. Social bonds focus the perception of risk in particular ways. A significant body of literature views risk perception as an individual phenomenon; there is almost no literature on risk perception as a social phenomenon.[82] Why are some communities able to face tremendous risks together with relative equanimity, while other communities experience tremendous anxiety about accepting tiny risks? One key element in the shaping of risk by the community is the sense of facing an inescapable, but shared risk. "When uncertainty is at a very high level and everyone is taking big risks, the cultural norms will encourage more risk-seeking."[83] Once one individual refuses to face the risk, or thinks of a reason why he should not face the risk while the others should, the sense of a shared risk begins to disintegrate, and each individual begins to feel that she is facing the risk alone. "When asked about the risks he takes, an individual has to make his answer start from some culturally established norm of due

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[82] Mary Douglas, Risk Acceptability According to the Social Sciences (New York: Russell Sage Foundation, 1985), 1.

[83] Ibid. p. 75.

carefulness...the more isolated a person, the weaker and more dispersed is his social network, the less his decisions are subject to public scrutiny, and the more he sets his own norms of reasonable risk. But as soon as there is a community, the norms of acceptability are debated and socially established. This activity constitutes the definitional basis of community."[84] Thus if the community defines a "high" risk as acceptable, social bonds influence the individual's perception of her personal risk as acceptable.

The medical profession is a loosely bound community[85] which may be involved in focusing risk perception in certain ways. The way in which the medical profession conceives of itself and the social bonds among its members may structure the debate about risk before the first question is asked, or the first "objective" data on transmission has been generated. Focusing solely on the objective danger while ignoring the institutional and professional structure in which this danger is confronted does not allow us to understand the perception of that danger. "The question of acceptable standards of risk is part of the question of

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[84] Ibid. p. 69.

[85] The medical profession is a heterogenous community which may be too loosely bound to structure risk perception significantly. However, smaller communities of medical professionals e.g. hospitals or professional societies, may define risks in very different ways.

acceptable standards of living and acceptable standards of morality and decency, and there is no way of talking seriously about the risk aspect while evading the task of analyzing the cultural system in which the other standards are formed."[86] If a physician feels assured that her actions in treating an AIDS patient are seen as "normal" and socially supported, she is unlikely to feel that her personal risk is overwhelming. If she feels that her professional group does not value AIDS care, and others around her avoid caring for AIDS patients, she will perceive her personal risk as greater.

Risk perception is linked to the institution in which the individual operates, and to how she perceives that institution. Doctors test their hospitals' good faith in assuring them that their risk will be close to nil if they use CDC precautions by matching promises to performance. If the institution promises to supply used needle containers in every room, but often a nurse has to walk to the next unit to find such a container, how reliable are the institution's guarantees of safety and how believable are its expressions of concern for its workers' safety? If the University of California doesn't want to test for aerosolized virus in the operating room, is it because the University is sure it isn't a risk, or is it because the University doesn't want

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[86] Mary Douglas, Risk Acceptability According to the Social Sciences (New York: Russell Sage Foundation, 1985), 82.

to know whether it's a risk or not? If the institution fails to back up its promises of helping to diminish individuals' risks, people perceive the risk they face as greater.

Another important element shaping risk perception is the community's ideas about justice. A person who feels fairly treated is less likely to perceive involuntary risks as overwhelming. "The threshold of risk acceptability in the workplace is lowered when the workers consider themselves exploited."[87] "Perhaps physical fears would not threaten to overwhelm citizens who felt confident of justice and social support. Perhaps people are not so much afraid of dying as afraid of death without honor."[88] Thus an institution that communicates to its workers that it thinks they are valuable, and offers tangible support of that position by providing the best protection available, is likely to have workers who perceive their risks as lower.[89]

This extended discussion of risk definition and perception points out that no solutions to the debate about what level of risk is "acceptable" are likely to be found.

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[87] Ibid. p. 5.

[88] Mary Douglas and Aaron Wildavsky, Risk and Culture (Berkeley: University of California Press, 1982), 6.

[89] This phenomenon may be part of the explanation for the difference in problems with avoidance of AIDS care by physicians, and compliance with CDC precautions at different Bay Area hospitals.

It also points out that arguments for physicians to treat AIDS patients based on labeling their fears as products of ignorance oversimplify a very complex phenomenon. A positive first step in furthering the debate about AIDS treatment would be to give up such rhetoric. Risk is not something easily defined; there is no magic number of "acceptable" risk. Individual risk perception differs from "objective" determinations of risk, but that does not mean that the perception of risk of HIV contagion is necessarily "wrong." Risk perception is a social phenomenon, linked to broader social issues of justice and morality. It is also influenced by institutional and community norms of carefulness and compassion. We should not be overly optimistic about the effects of further education about risks of transmission on the perceived risk of occupational HIV infection, although this education has probably been responsible for some of the decrease in fear to date at Bay Area hospitals. Faith in education stems directly from the notion of people's risk perceptions as a problem of misperception. As we have seen in the above discussion, this characterization is oversimplified. We can, however, be optimistic that social and institutional changes that make doctors more confident that their work with AIDS patients is valued, and that their own lives are valued will do much to change their perception of their risk from HIV.

PART IV: SOURCES OF PHYSICIANS' RESPONSIBILITIES IN MODELS OF MEDICAL PROFESSIONALISM AND THE DOCTOR-PATIENT RELATIONSHIP

An understanding of the ways society and individuals construct risk does not allow us to be content to develop societal expectations of physicians' behavior towards AIDS patients on the argument that risk is low and therefore physicians ought to be willing to treat AIDS patients as a normal part of their medical practice. Society and the medical profession must therefore search for another basis on which to formulate expectations of physicians. A seemingly fruitful way in which to develop such expectations is by looking at the way in which models of both medical professionalism and the doctor-patient relationship approach related ethical issues, and the implications of the values emphasized in each model for acceptable physician behavior in providing care to AIDS patients. These models embody the values which the society and the profession emphasize as important in being a doctor and entering into relationships with patients. Thus, for example, most notions of medical professionalism include the sense that doctors are society's agents in assuring medical care for those whom society wants cared for.[90] One value enshrined in most models of the doctor-patient relationship is that doctors must act in their patients' best interests. Different models of medical professionalism and the doctor-patient relationship exist

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[90] In the U.S.A., society does not assure health care for all its members.

and each emphasizes different values. Comparing and contrasting the different models allows us to determine whether any values relating to the care of AIDS patients are found in all of these models.

This section of the paper describes different models of physicians' obligations to ill people, and different models of the doctor-patient relationship. It then describes actions of physicians in prior epidemics, modern professional codes, and policies of Bay Area hospitals that reflect these different models. It concludes that two models of medical professionalism have coexisted throughout much of the history of medicine in this country, and since each model leads to different conclusions about the obligations of physicians to accept AIDS patients, no one model provides an adequate underpinning for a coherent medical ethic regarding initiating a relationship with AIDS patients. In addition, I find that though the contractual model of the doctor-patient relationship is currently in the ascendancy, it does not correspond enough to the reality of health care delivery at the present time to provide an adequate basis for developing responsibilities of doctors to AIDS patients within a preexisting doctor-patient relationship.

Models of medical professionalism and the doctor-patient relationship reflect values operative in two different spheres. Models of medical professionalism

reflect the profession's relationship to society. They attempt to provide answers to questions of physicians' obligations in initiating relationships with patients, and the profession's and individual physicians' responsibilities to provide access to medical care. Models of the doctor-patient relationship focus on values important in an established relationship between a physician and patient. They thus focus on values such as adequate communication, informed patient decision-making, and commitment of the physician to an ongoing relationship with the patient.

However, these two realms of responsibilities may work additively, or requirements of one model of professional ethics may lessen the impact of requirements suggested by one of the models of the doctor-patient relationship. Society's interest in who becomes a patient may impact the doctor-patient relationship. For instance, a doctor may have numerous responsibilities to a patient within an established relationship, but none to a new patient needing care, if society views the provision of medical care as a responsibility only of the medical profession as a whole, and allows individual doctors to choose who they will and will not treat.

There is also a third realm of physicians' responsibilities, especially important in today's health care market, in which doctors have responsibilities to third-party payors, to the government, to employers such as

HMOs, and to hospital cost-containment authorities. The influence of these parties plays a large role both in determining who enters into relationships with doctors, and the scope of physicians' responsibilities to patients once the relationship has been established. Because there are myriad different relationships between doctors and employers, insurance companies, the government, and those in charge of hospital economic control mechanisms, a full discussion of the impact of these relationships on the provision of health care is beyond the scope of this paper. Suffice it to say that such relationships are critical in determining both who will receive care and the kind of care they will receive.

A. Models of Medical Professionalism

In addressing physicians' responsibilities to patients with AIDS, we must ask whether being a professional entails different responsibilities than those required of a non-professional. What does it mean to be a medical professional? Does the definition of professionalism inform us about the duties of professionals in different situations? Does this definition provide a grounds from which to derive acceptable norms of behavior towards AIDS patients? If we find that doctors are no different than any other human being by nature of becoming a professional, this

does not force us to conclude that doctors then have no duties to treat AIDS patients. But it does mean that these duties do not arise from their sense of themselves as medical professionals, though duties may still be derived from their sense of themselves as "good" human beings.

Definitions of professionalism tend to stress five elements: formal education beyond the ordinary, knowledge based on a systematic theory that is not available to the average individual, adherence to a commitment to serve the client's interest and not just one's own, community-sanctioned monopoly power, and authority over the client.[91] In addition, professions are usually seen as self-regulating. The profession controls access to its expertise. Usually the expertise concerns matters of the highest importance e.g. life and death, and knowledge is based upon a systematic body of theory which must be mastered to be a professional. Since this expertise is important and access to it is controlled by the profession, possessing this expertise necessarily gives the professional power. There is always the possibility that this knowledge could be used in ways that would not benefit the patient;

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[91] David Ozar, "Social Ethics, The Philosophy of Medicine, and Professional Responsibility," Theoretical Medicine 6:281-294.

Ernest Greenwood, "The Attributes of a Profession," Professionalization, ed. Howard M. Vollmer and D. Mills (Englewood Cliffs, New Jersey: Prentice-Hall, Inc., 1966), 10-18.

society seeks to control professionals' power to assure that their expertise is not used inappropriately. People who join the profession of medicine make a public commitment, by taking an oath, to act in certain ways. Joining a profession involves acting according to established standards. In theory, a professional cannot choose which standards she wishes to adhere to; choice is *only* involved in the decision of whether to join the profession or not.[92] The Hippocratic Oath, the most commonly used articulation of acceptance of the norms of the medical profession by medical school graduates, stresses two categories of duties: to patients, and to teachers and other members of the profession. Physicians undertake duties to patients and they owe a debt to their teachers for the knowledge gained from them.[93] The profession as a whole thus has a relationship with society in which society grants the profession a privilege e.g. a monopoly over the provision of health care to the sick, and the profession encodes its responsibility not to abuse this monopoly power in codes and oaths which are published or uttered in a public forum. These codes represent the tangible expression of society's expectations of the profession. Thus a professional differs from a non-

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[92] David Ozar, "Social Ethics, The Philosophy of Medicine, and Professional Responsibility," Theoretical Medicine 6:281-294.

[93] William F. May, The Physician's Covenant (Philadelphia: The Westminster Press, 1983), 10.

professional in that society has granted the professional power, and has required that the professional adhere to public oaths or codes of conduct that regulate how she uses this power. Thus these codes or oaths are important statements of the responsibilities of medical professionals that may give us a sense of what responsibilities physicians might have to AIDS patients.

However, modern codes of medical professional organizations do not share one underlying conception of physicians' obligations to ill people. Two competing conceptions of the medical profession's responsibilities in caring for ill people exist, each with many adherents and many years of history.

Dr. Cooke labels the two competing conceptions of the medical profession's responsibilities as "contractual" and "categorical."[94] The contractual formulation refers to a social contract to which physicians are a party. In exchange for social privileges and a monopoly on the provision of medical care, society expects that the profession as a whole will regulate itself and meet the needs of sick people. This social contract is not with each individual physician, but with the profession as a whole. Thus an individual doctor can decide whether or not she

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[94] Molly Cooke, M.D., Chair, Ethics Committee, San Francisco General Hospital. Grand Rounds, University of California, San Francisco, January 19, 1989.

wishes to treat an individual patient, as long as access to medical care for that patient is not compromised. The ethical commitment of the doctor to the patient is discharged by referral in this formulation.

One of the primary values reflected in this conception of medical professionalism is an individual doctor's right to decide the kind of practice in which she wishes to engage. This model places a high value on allowing individual doctors and patients to develop their own relationships, rather than being required or assigned to each other.[95] This model reflects the historic autonomy of the medical profession in this country, and its unwillingness to regulate the ways in which individual doctors structure their work life.[96] The profession has historically had a great deal of freedom from social requirements on its members, and has placed a high premium on the individual autonomy of its members. Thus the contractual model of medical professionalism corresponds to how the medical profession has conceived of itself through much of its existence in this country.

The contractual model can be construed as allowing

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[95] This model, thus, may correspond less to actual medical practice at present, since more and more patients and physicians have less choice, due to financial constraints by government or third-party payors, about the kinds of relationships into which they may enter.

[96] Paul Starr, The Social Transformation of American Medicine (New York: Basic Books, Inc., 1982).

physicians to decide who they will and will not treat providing that they do not make this decision based upon characteristics such as race or sex[97], and providing that they refer patients to doctors willing to treat them. The contractual model would thus support the right of physicians to refuse to care for AIDS patients providing that the patients were referred to willing physicians, and providing that society did not recognize positive HIV-status as a protected state such as race or sex.[98]

The "categorical" formulation assumes that each physician has a duty to each patient which is integral to the practice of medicine. Thus, the very fact of a patient's illness provides a claim upon the doctor. This model then places a high value on a physician's willingness to treat all comers as a necessary condition for professionalism.[99] Under the categorical model of medical professionalism, society expects that physicians treat all

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[97] Race and sex are considered "suspect classifications" under constitutional law, and decisions about whether or not to treat a patient on these grounds would likely be found to be discriminatory and impermissible, especially if a publicly-funded hospital were involved.

Courts will subject governmental attempts to classify persons on race or gender grounds to "strict scrutiny." This means that the court will uphold the classification scheme only if the government shows that it is necessary to achieve a compelling governmental interest.

[98] See page 96 for further discussion of HIV status as a protected state.

[99] Erich H. Loewy, "Duties, Fears and Physicians," Social Science and Medicine 23(8):827-832.

patients who ask for treatment regardless of any mitigating factors other than the physician's lack of competence to treat a particular problem. Thus, society would not accept a doctor's referral of an AIDS patient with a problem within her expertise to a willing colleague as a discharge of her duty under a categorical model of medical professionalism.[100]

Statements of professional organizations regarding the responsibilities of physicians in treating AIDS patients show the coexistence of these two models of medical professionalism. Some of the statements of professional organizations on the issue of whether doctors can refuse to treat AIDS patients assume a categorical approach to the issue; others assume a contractual model of obligations.

The American College of Physicians (ACP), the Infectious Diseases Society of America, and the American Association of Medical Colleges (AAMC) have adopted categorical positions. The AAMC's statement reads in part, "Medical students, residents, and faculty members have a fundamental responsibility to provide care to all patients

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[100] Of course, even in this formulation, a doctor could refer most or all of her AIDS patients and argue that she needs special training in treating AIDS to be able to care for them. At the same time, she might make no effort to get such training or inform herself about the disease. However, such an argument would be difficult to make in refusing to treat asymptomatic HIV-infected patients.

assigned to them, regardless of diagnosis.[101] A failure to accept this responsibility violates a basic tenet of the medical profession--to place the patient's interest and welfare first."[102] The ACP and the Infectious Diseases Society state:

> The American College of Physicians and the Infectious Diseases Society of America believe that physicians, other health care professionals, and hospitals are obligated to provide competent and humane care to all patients, including patients with AIDS and AIDS-related conditions as well as HIV-infected patients with unrelated medical problems. The denial of appropriate care to patients for any reason is unethical.[103]

The proposed bylaws change at San Francisco General also represents a shift from grounding physicians' responsibilities at that hospital on a contractual model to grounding them on a categorical model. Individual departments will no longer be primarily responsible for providing care; the obligation will fall upon each individual physician. Thus even if a department had been able to assure care in the past, individuals who had avoided

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[101] A patient is "assigned" to different residents and medical students working in "teams" depending on which team is "on call" to work up new admissions at the time of admission of the particular patient.

[102] Association of American Medical Colleges, "Professional Responsibility in Treating AIDS Patients: Position Paper," Journal of Medical Education 63:587, 589-90.

[103] Health 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). Position Paper," Annals of Internal Medicine 108:460-469.

caring for AIDS patients will now be required to treat AIDS patients if the bylaws change passes.

On the other hand, the statement of the American Medical Association (AMA) on whether a physician can refuse to treat an AIDS patient is more contractual. In 1847, the AMA published its first code of professional ethics which contained an explicit duty to face personal risk in the line of work. The code stated "...and when pestilence prevails, it is their [physicians'] duty to face the danger, and to continue their labors for the alleviation of the suffering, even at the jeopardy of their own lives."[104] In 1957, this section was deleted from the revised AMA Code of Ethics, and no other modern AMA codes mention a physician's duty to accept personal risk.[105] The first limitation on a physician's right to refuse to treat a patient in the era of AIDS was in the statement of the AMA's Council on Ethical and Judicial Affairs published in December, 1987. A portion of this statement reads:

> "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'...Physicians should respond to the best of their abilities in cases of emergency where first-aid

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[104]Abigail Zuger and Steven H. Miles, "Physicians, AIDS, and Occupational Risk: Historic Traditions and Ethical Obligations," Journal of the American Medical Association 258(14):194-1928.

[105] Ibid.

> treatment is essential, and physicians should not abandon patients whose care they have undertaken."[106]

The Council's statement clearly states that refusing treatment on the basis of seropositivity is not permissible in cases where a doctor-patient relationship exists and in cases of emergency. It does *not* impose an explicit duty on physicians to accept new HIV-positive or AIDS patients, except in cases of emergency.[107] Thus it recognizes a duty to treat arising from an established doctor-patient relationship, but it does not recognize that physicians have an obligation to accept new patients without regard to their HIV status. It thus recognizes a duty to treat as arising within an established doctor-patient relationship, and not as a constituent obligation of becoming a medical professional. The code continues:

> 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...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."

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[106] American Medical Association Council on Ethical and Judicial Affairs, "Ethical Issues Involved in the Growing AIDS Crisis," Journal of the American Medical Association 259(9):1360-61.

[107] Providing medical treatment to any patient in an emergency, regardless of other factors, is a legal requirement of medical practice.

The AMA statement reiterates a physician's right to choose whom she wishes to treat, and recognizes that she has discharged her duty as a medical professional to a patient by referral to another physician. It places physician autonomy higher than any claim an individual patient might exert upon an individual physician by virtue of the patient's illness. Though the code theoretically would not allow physicians to deny care to every patient infected with the AIDS virus who sought their services, any plausible excuse would likely be acceptable in a referral of an AIDS patient.[108] Thus the AMA code does not recognize an individual duty to treat new patients regardless of infectious status as a constituent obligation of becoming a medical professional.

Alta Bates Hospital has based its proposed bylaws change on a contractual model of medical professionalism. By allowing departments to decide how and by whom care will be delivered to HIV-infected patients, the hospital does not place the responsibility to treat on individual doctors.

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[108] The AMA's top officials have made it clear that they have no plans to enforce the above provisions requiring that physicians not categorically refuse to treat based solely on seropositivity. If a doctor refuses to treat an HIV-positive patient, she will be found "incompetent" to render care and will be excused from treating the patient. Obviously if the AMA has no intention of enforcing its own guidelines, then physicians, while paying lip service to treating HIV-infected patients, will be able to refuse to treat them with no fear of professional sanctions. George Annas, "Legal Risks and Responsibilities of Physicians in the AIDS Epidemic," Hastings Center Report, April/May, 1988, 26-32.

Thus if all doctors but one in any one department refuse to treat HIV-infected patients, but the one doctor is willing to see all of the HIV-infected patients needing care in that specialty area, this solution is acceptable to the hospital. The hospital thus recognizes the provision of medical care to new patients to be an obligation only of the profession as a whole, and not an obligation of each individual doctor.

Modern codes of professional groups and policies of Bay Area hospitals reflect the coexistence of these two models of medical professionalism. Neither model is either "wrong" or "right"; each reflects important and widely held values in medical practice. But expectations of physicians based on one model may be quite different than expectations based upon the other model.

B. Historical Responses in Prior Epidemics

The history of physician responses in past epidemics has been used as a basis on which to ground a duty to treat AIDS patients.[109] However, the history of physicians'

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[109] Erich Loewy, "Duties, Fears and Physicians," Social Science and Medicine 22(12):1363-1366.
Chris G. Petrow, "The Physician's Ethical Obligation to Take Care of Patients in Times of Plague," [letter], Journal of the American Medical Association 259(9):1325-1326.
Jerome H. Kim and John R. Perfect, "To Help the Sick: An Historical and Ethical Essay Concerning the Refusal to Care for Patients with AIDS," The American Journal of Medicine 84:135-138.

responses in prior epidemics does not provide a clear record of physician behavior based either on a contractual or a categorical notion of medical professionalism.[110] Though overall it seems that many physicians stayed on the job throughout past epidemics, significant numbers fled, often including the most prestigious members of the profession. Some who stayed apparently felt a moral or religious obligation to stay.[111] Some doctors stayed because the epidemics represented financial opportunities. These doctors made contracts with governing bodies specifically to work in epidemic areas in return for money or special privileges.[112] Others remained in plague areas because they couldn't or didn't want to move.[113] Some who fled defended their actions by explaining that they were following their patients (usually the wealthy classes) as they left town.[114] During most historical epidemics physicians did realize the contagious nature of the diseases they were treating. Thus,

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[110] Daniel M. Fox, "The Politics of Physicians' Responsibility in Epidemics: A Note on History," Hastings Center Report, April/May 1988, 5-10.
Erich H. Loewy, "Duties, Fears and Physicians," Social Science and Medicine 22(12):1363-1366.

[111] Abigail Zuger and Steven H. Miles, "Physicians, AIDS, and Occupational Risk: Historic Traditions and Ethical Obligations," Journal of the American Medical Association 258(14):1924-1928.

[112] Ibid. p. 1925.

[113] Ibid. p. 1925.

[114] Ibid. p. 1925.

they did not continue to work out of ignorance of the risk to themselves.

In many cities, the community did expect each individual physician to attend to the sick, without regard for his own health. In 1382, Venice passed a law that forbade physicians to leave the city in times of plague.[115] During the yellow fever epidemic in Philadelphia in 1793, Benjamin Rush wrote of his obligations to his sick patients as being equivalent to familial obligations in times of hardship.[116] During the cholera epidemics of the 19th century, the outbreak of influenza in 1918, and the polio epidemic of the 1950s, very few physicians turned away from sick patients. Thus, in many instances, physicians have responded to an epidemic disease as individuals with individual responsibilities to patients. They have conceived of their obligations to sick patients as adhering between an individual patient and an individual doctor.

Documents from various past plagues reflect a sense of social outrage at doctors who left town during the plague.[117] When some doctors returned after the plague danger abated, they had difficulty regaining patients and were censured by the public. Guy de Chauliac, writing about the Black Death,

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[115] Ibid. p. 1925.

[116] Ibid. p. 1926.

[117] Erich H. Loewy, "Duties, Fears and Physicians," Social Science and Medicine 22(12):1363-1366.

said "...and I , to avoid infamy, dared not absent myself but with continual fear preserved myself as best I could."[118] Fear of censure outweighed fear of disease and de Chauliac stayed on the job. Thus, historical documents reflect a consensus in some societies that individual physicians have responsibilities in times of plague that are not necessarily relieved by the presence of adequate numbers of doctors who are willing to treat.

However, in a number of cities in times of plague, plague doctors were appointed by local governing bodies. These doctors were municipal employees who were given a home, a salary and citizenship in return for a promise to visit all patients regardless of their illness.[119] Appointment of these plague doctors relieved their colleagues of the obligation to visit patients stricken with the plague. In these situations, the society viewed the profession as a whole to be responsible for treating plague victims. Individual doctors were not necessarily responsible, as long as enough plague doctors could be recruited to treat the sick. The contractual formulation thus underlay this historical solution to the problem of providing care to the sick.

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[118] Ibid. p. 1365.

[119] Daniel H. Fox, "The Politics of Physicians' Responsibility in Epidemics: A Note on HIstory," Hastings Center Report April/May 1988, 5-9.

The history of physician response to epidemics is thus a checkered one, which reflects the two senses of professional ethics, the contractual and the categorical, that guided both societal and individual physician decision-making in different epidemics. These two notions of medical professionalism then have a long history of coexistence.

C. Legal Conceptions of Physicians' Responsibilities in Accepting New AIDS Patients

Legal conceptions of physicians' responsibilities in initiating relationships with patients rest on the contractual model of medical professionalism. Under common law, no physician can be required to accept a particular person as a patient. However, the common law's emphasis on the right of the physician not to be forced to take any particular patient may be overridden if the patient is HIV-positive. The Supreme Court, in deciding School Board of Nassau County v. Arline, suggested that HIV seropositivity would be a protectable handicap under Section 504 of the Rehabilitation Act of 1973.[120] Therefore, HIV status may differ from other reasons for refusing to initiate a physician-patient relationship. Physicians might be guilty of discrimination if they refused to accept an

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[120] Neil Albert, "A Right to Treatment for AIDS Patients?" 92 Dickinson Law Review, Summer 1988, 743-776.

HIV-positive patient, but would not be if they refused to initiate a relationship with an obese patient (unless obesity were found to be a handicap).[121] Section 504 reads,

> No otherwise qualified handicapped individual in the United States, as defined in section 706(7) of this title, shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.[122]

Hospitals which receive federal funds would thus likely be subject to the provisions of Section 504 of the Rehabilitation Act of 1973 and could not refuse to treat a patient positive for HIV. However, hospitals are unlikely to adopt policies that discriminate against HIV-infected patients. The phenomenon of refusals to treat HIV-infected patients has been one of individual doctors refusing to treat, not one of institutions turning away HIV-positive patients. Thus if the medical staff <u>as a whole</u> can meet its requirement of providing access to care for HIV-infected patients, any amount of care-shifting within the institution can occur without legal sanctions, unless the patient can show that the care-shifting harmed her.

Individual private doctors may be beyond the reach of

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[121] If there were no risk of transmission of the virus to the physician, refusing to treat on the basis of HIV status would be equivalent to refusing to treat on the basis of race or sex. However, it would be up to the courts to decide if the risk of transmission warranted the refusal to treat.

[122] 29 U.S.C. 794(1978)

Section 504 of the Rehabilitation Act of 1973, since they do not ordinarily receive federal financial assistance. Conceivably doctors could be held to this standard if they accept payment for services rendered to MediCare and Medicaid patients, but this remedy is speculative. Under common law, then, a physician does have the right to refuse to accept an HIV-infected individual as a patient, unless the conduct is held to be discriminatory under the Rehabilitation Act of 1973.

Under statutory and common law, doctors working in emergency rooms are required to treat all patients who arrive with a medical emergency. They do not have the right to refuse to treat an individual in a life-threatening emergency on the basis of HIV status. However, once the emergency ends, the relationship of the emergency room doctor to the patient ends also, and that physician has no continuing obligation to the patient. Thus, this limitation of a doctor's right to refuse to treat new patients is quite circumscribed.

The modern professional codes, statutory and common law, and the history of the profession vary in the requirements they impose upon doctors to initiate treatment of AIDS patients, and reflect the two differing professional notions of obligations to ill people within the profession. Individual doctors then have support for either a right to refuse to treat new HIV-infected patients or a duty to treat

HIV-infected patients who seek their services, depending upon which code they base their argument. The policies adopted by various different Bay Area hospitals also reflect the tension between these two different conceptions of physicians' obligations to sick people. Those hospitals which have allowed individual doctors to make the decision about treating AIDS patients, as long as each department can assure access to care, have developed a policy based upon conceiving of the obligation as between the profession as a whole and society. Those hospitals which have required individual doctors to treat, or individual departments that have required all members of the department to treat, base their policy upon an understanding of the obligation as between each physician and each patient.

An alternative argument is that doctors cannot categorically refuse to treat HIV-infected patients in either model of the profession, but for a different reason in each model. Using the categorical model, physicians have an obligation to provide care stemming from their obligation to each individual patient. They thus do not have the right to deny care to someone in need of that care if the problem is within their competence. In the contractual model, it is only the medical profession as a whole that has the obligation to provide medical care; individual doctors can shift their care responsibilities to their colleagues, as long as some doctor is available to provide the care.

However, even if doctors conceive of their responsibilities to patients as arising from the contractual model, individual doctors might still have to provide care to a certain number of HIV-infected patients. This responsibility might arise from the neglected obligation to other physicians which is part of the Hippocratic Oath, or from other codes' implicit sense of professional community. The debt to teachers and the sense of reciprocal obligation and community between physicians arising out of referrals and consultations might require that physicians do not ask their colleagues to incur extra risk so that they may incur none. Some who fear contracting AIDS occupationally view the question of whether a physician may refuse to treat an AIDS patient as a purely individual issue. However, implicit in every code of professionalism is a sense of reciprocal obligation between doctors, a sense of professional community. Thus, this issue should be defined as one to which the community as a whole should respond. The medical profession is a closed community; we cannot recruit new individuals from somewhere "out there" to take on the risk. Our recent focus in medical ethics has been on obligations of the physician to the patient. What has been shoved aside is obligations of physicians to each other, the equal obligation stressed in the Hippocratic Oath.

D. Models of the Doctor-Patient Relationship

Notions of medical professionalism reflect who becomes a patient. Once an individual physician and patient have entered a relationship, social and philosophical models of the doctor-patient relationship represent different attempts to reflect the important values in this individual relationship. Again, responsibilities arising from the codes of medical professionalism, and the economic and other social pressures upon individual doctors and patients also impact this relationship. In addition, even if a doctor has the obligation to provide care to a patient at personal risk within an established relationship, it does not necessarily follow that she has any such obligation to a new patient first seeking her services.

Different models of the physician-patient relationship have attempted to highlight important values within an established doctor-patient relationship, such as patient informed decision-making, physician actions aimed solely at benefiting the patient, and adequate communication between the doctor and patient. These models also reflect values important in the debate about physician responsibilities in providing care to AIDS patients.

"Older" notions of the doctor-patient relationship viewed it as almost akin to a parent-child relationship.[123]

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[123] William F. May, The Physician's Covenant (Philadelphia: Westminster Press, 1983), 25.

Patients were made dependent by the fact of their illness; physicians had authority over patients by virtue of their medical training and technical expertise. The primacy of science underlay this conception. The doctor commanded knowledge that the patient could never approach.[124] This conception of the doctor-patient relationship entails the view that patients are incapable of making their own decisions about medical care. Doctors are invested with the power to make decisions for the patient. The patient's responsibilities within this relationship are to follow doctors' "orders" and to heal. The doctor's responsibilities are to place the patient's needs before her own, to provide technically competent care, and to protect the patient from harm. This model thus values altruism from the doctor and obedience from the patient. Though a physician could still view her obligations in accepting a patient as arising either from a categorical or contractual model of responsibilities towards sick people seeking care, it seems clear that once the doctor-patient relationship is established, if it is conceived of as a parent-child relationship, the doctor has an obligation to provide care for her AIDS patients, even at some personal risk to herself. She might still be free to reject new AIDS patients. Her responsibility within an established parent-

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[124] Eric J. Cassell, "The Changing Concept of the Ideal Physician," Daedalus 115(2):185-208.

child doctor-patient relationship is to put the patient's needs first. The patient's need for care will almost always (except perhaps if the risk for the doctor is suicidal) outweigh the doctor's need for self-protection. In return for this altruism, the doctor is rewarded with enormous prestige and power to make decisions for patients.

In the last twenty years, the parent-child model of the physician-patient relationship has been criticized based on arguments against paternalism.[125] Information about health and disease has become less exclusive and more accessible to patients.[126] Patients have increasingly sought a voice in decisions about their own medical care. Autonomy rights of the patient have been stressed within new models of the doctor-patient relationship.

The most common model of this new doctor-patient relationship is that of a contract between independent agents. The contract model assumes rough parity between the parties. This model stresses the importance of patient autonomy in medical decision-making, and of the physician's obligation to provide sufficient information to the patient to allow her to make informed choices. It rejects doctors' claims to paternalistic authority within the doctor-patient

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[125] Howard Brody, "The Physician-Patient Relationship: Models and Criticisms," Theoretical Medicine 8:205-220.

[126] Eric J. Cassell, "The Changing Concept of the Ideal Physician," Daedalus 115(2):185-208.

relationship. The legal physician-patient relationship under common law is based upon an implied contract that the private physician will use reasonable care and expertise, and the patient will pay the bill.[127] Hospitals and HMOs seek to assure patient autonomy by instituting informed consent procedures for most medical treatments (although adherence to such protocols varies). Thus the contractual model of the doctor-patient relationship is widely used when delineating patient rights in a number of different health care settings.

Little attention has been focused on whether such a contractual model of the physician-patient relationship also implies that the doctor has autonomy rights within the relationship. Does a contractual relationship decrease the responsibilities of a physician for a patient? Does the physician have the right to refuse to do procedures that pose a risk to her health? Does she have the right to refuse to treat patients with whom she has had a prior therapeutic relationship for any reason? If the doctor and patient who have entered into the contract are viewed as mutually disinterested parties who are contracting in order to better further each one's individual needs, the responsibilities of the physician to the patient may be lower than they were in the parent-child model of the

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[127] Neil L. Albert, "A Right to Treatment for AIDS Patients?" 92 Dickinson Law Review, Summer 1988, 743-776.

relationship. If the patient presents a risk to the doctor that she finds unacceptable, she may be able to sever the relationship with due notice to the patient, if this action is allowed in the contract. The doctor still has the responsibility not to harm the patient, and therefore must provide a proper interval and referral to another physician when the relationship is severed. However, the terms of the contract may specify that the patient also has the responsibility not to harm the doctor. Thus an HIV-positive patient who conceals that fact from the doctor might be voiding the contract by concealing a fact of potential consequence to the doctor.

Contracts between doctors and patients are not usually written documents. Doctors and patients often assume that the other party has responsibilities that are never explicitly stated. Thus the parameters of this contractual model of the doctor-patient relationship are difficult to specify. The doctor would seem to have less obligation to place the patient's welfare above any risk to her own health than she would have in a paternalistic doctor-patient relationship, but how much personal risk she would be obligated to take is difficult to discern. If we subscribe to a categorical professional ethic, in which each patient has a claim upon each doctor's services, the amount of risk the society would expect a doctor to take, even in a contractual doctor-patient relationship would presumably be

greater (since society would recognize the claim of sick people upon doctors as a primary value) than if the society recognized a contractual professional ethic which placed physician autonomy paramount. Thus the boundaries of physicians' responsibilities in a contractual doctor-patient relationship may vary depending on which professional ethic is paramount.

The contractual model is certainly the model of the doctor-patient relationship currently in the ascendancy. However, there are a number of problems with this model that make it a questionable choice as the most accurate model of the doctor-patient relationship, and therefore a poor basis on which to develop physician responsibilities in treating AIDS patients. First, the number of patients who enter into physician-patient relationships freely and by individual choice is small and limited to the upper classes of our society. More and more people are receiving health care in health maintenance organizations (HMOs) and preferred provider organizations (PPOs) in which they have limited choice of physicians. In addition, the large numbers of uninsured and MediCaid patients in this country also have little or no choice about the medical care they receive. Those without insurance must often present themselves at the emergency room for treatment and hope for the best. They have no choice of physician, and they are often treated in a rushed, impersonal environment in which concern for patient

autonomy may be secondary and informed consent may be perfunctory. MediCal compensation for some health care services is now so low that some doctors accept very few or no MediCal patients. A pregnant MediCal patient in Oakland may find, depending on the month, that there are simply no obstetricians in the area who will accept her as a patient, and the community clinics have waiting lists of 4 months. Where is her autonomy? AIDS patients are often on MediCal. They too often have little choice of physician or hospital. They are dependent on the physician for access to life-prolonging AZT and experimental treatments which they may wish to try. They have few alternative providers with whom to contract. Thus to characterize the doctor-patient relationship as a contract between free and equal moral agents does not correspond to reality except for a select number in our society. Particularly in the context of AIDS, patients are often not free agents, and therefore arguments for physician autonomy rights within this model lose considerable force.

Another problem with the contractual model of the physician-patient relationship is that usually when a patient seeks to establish a relationship with a physician, it is because he has experienced some decrease in his health and functioning. Often the patient's life may be in danger. Clearly the stakes are inevitably higher for the patient than the physician in the relationship. The argument that

physicians and patients are equal, autonomous agents in contracting for health care does not take into account the fact that "...persons who are sick experience their illness as a lessening of their autonomy."[128] They thus come to physicians partly in an attempt to regain their sense of autonomy. Though it will usually be good business for the physician to place a high value on the particular patient's life and health, this value does not necessarily have primacy in the contractual model.[129] Instead, the contractual model stresses the obligation of the physician to provide technically competent care as a primary value.

The argument for a contractual model of the physician-patient relationship also does not take into account the inevitable cultural authority entailed in the role of the physician in this society. Paul Starr defines cultural authority as "the probability that particular definitions of reality and judgments of meaning and value will prevail as valid and true."[130] Patients consult physicians to find out the meaning of their symptoms and whether they are "really sick." The physician shapes the patient's understanding of his own experience by labeling him as sick, or well, or

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[128] David T. Ozar, "Patients' Autonomy: Three Models of the Professional-Lay Relationship in Medicine," Theoretical Medicine 5:61-68.

[129] Ibid.

[130] Paul Starr, The Social Transformation of American Medicine (New York: Basic Books, 1982), 13.

malingering. Certainly a patient is often free to reject the physician's characterization of his experience, but we should not underestimate the power of a doctor's definitions of patients' experiences.

The contractual model of the doctor-patient relationship does not apply to the many situations in which patients are forced to accept the doctor's cultural authority.[131] Physicians make judgments as to what constitutes disability, insanity, death, and illness that carry profound implications for courts, employers, the military, and other social authorities. A patient here is not free to contract with the physician for specific services. The judgments of the physician determine what happens to the patient. Thus the doctor is, by nature of her role as a gatekeeper, and by her authority to define the very nature of a patient's experience, in a position of authority over the patient. The patient is dependent on the physician to label her appropriately. This dependence is often inherent in the doctor-patient relationship, and makes the patient unable to participate as an equal moral agent in a contract with a physician. The contractual model is thus an imperfect vision of the way in which medical care is delivered to the majority in this country. Basing physician rights on this model of the doctor-patient relationship is

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[131] Ibid. p. 15.

therefore problematic.

These two models of the physician-patient relationship suggest that physicians have different responsibilities to patients depending on how they conceive of their relationship with their patients. If the doctor-patient relationship is paternalistic, it is fairly clear that the doctor has the duty to treat AIDS patients, even at personal risk. However, to return to a paternalistic model of the doctor-patient relationship in order to derive a basis for a duty to treat AIDS patients would require an unacceptable sacrifice of the patient autonomy rights that we have come to expect within the physician-patient relationship. If the relationship is purely contractual, the doctor may have the right to refuse to treat patients who pose some risk to the doctor, but at what level of personal risk is not clear. However, such a model is not an accurate enough representation of reality to afford an adequate basis for such a right to refuse to treat AIDS patients. Thus neither of these models of the doctor-patient relationship provides an adequate basis for either a duty to treat or a right to refuse treatment to HIV-infected patients.

One final addition to the doctor-patient relationship discussion is a comparison of the conceptions of the doctor-patient relationship in medicine and surgery. Primary-care physicians are necessarily patient-oriented. Surgeons are

procedure-oriented.[132] No one expects the surgeon to maintain an on-going relationship with the patient after recovery from the surgery is complete. She is asked to provide a necessary procedure by the patient's physician; the surgeon then decides the risks and benefits of the proposed procedure for the patient, and the patient gives informed consent to the surgery. Surgeons may in fact base their sense of professionalism more on finding "meaning in performance per se" than on any sense of a continuing relationship with the patient.[133] Their primary relationship may not be to the patient, but to the surgery itself.[134] In the surgeon-patient relationship, if the risk to the patient from the surgery outweighs the potential benefits to the patient, the surgeon may refuse to do the procedure and leave the patient. She is not bound to follow the patient's wishes if the surgeon thinks the surgery is contraindicated. Thus surgeons may "abandon" patients both after recovery from the surgery is complete, and if the surgery is not indicated. Thus ethics based on the physician-patient relationship may be irrelevant to the experience of many

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[132] Molly Cooke, M.D., Chair, Ethics Committee, San Francisco General Hospital. Grand Rounds, University of California, San Francisco, January 19, 1989.

[133] William May, The Physician's Covenant: Images of the Healer in Medical Ethics (Philadelphia: The Westminster Press, 1983), 87.

[134] Molly Cooke, Chair, Ethics Committee, San Francisco General Hospital. Grand Rounds, University of California, San Francisco, January 19, 1989.

surgeons.

Are there any situations in which a doctor's duty to treat, even within a paternalistic model of the doctor-patient relationship, is lessened? It seems plausible to say that a doctor's duty to treat a patient is decreased if the patient threatens the doctor with physical harm. Must the five-foot-two-inch doctor continue to try to initiate a physical exam when the six-foot-four-inch, 250-pound patient has said "come one step closer and I'll smash your face in?" In this scenario, the patient's illness is an important component of the debate. If the patient is suffering symptoms consistent with a possibly serious disease, the doctor's obligation to treat in the face of the threat of physical harm presumably increases. However, if the patient is suffering from what looks like a mild case of poison oak, the doctor's duty to treat in the face of threats to her physical health would arguably be less. In the scenario of serious disease, the doctor still might not have to treat the patient herself, but she would be duty-bound to assure that the patient received care from someone (perhaps the patient would not threaten the next health care worker). In the case of the rash, even the duty to refer might be lessened.

In this scenario, the two ends of the spectrum of threat to the doctor may be clear, but there is a large area where the threat of harm to the doctor is ill-defined, or

low but not zero. The doctor's duty to treat in these instances is not clear. Dr. Cooke at San Francisco General would grant physicians the right to refuse to treat an HIV-positive patient who requested bunionectomy. She bases this position on the fact that adequate non-surgical treatment exists for the condition, and the condition is not life-threatening or particularly disabling.[135] Dr. Day at San Francisco General feels that if she can refuse to do bunionectomies, then she ought to be able to refuse to do some hip replacements. This difference of opinion reflects the problems in quantifying the amount of benefit to the patient versus risk to the physician, and its relationship to a duty to treat.

Dr. Day argues that the patient's life expectancy also ought to be a part of the equation. If the patient's life-expectancy is under a year, she believes the surgeon's obligation to provide certain operations decreases. The benefit to the patient is less because by the time he recovers from the operation, he will have little time left to benefit from it. This smaller amount of benefit becomes outweighed by the possibility of harm to the physician, and therefore the surgeon may refuse the operation.

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[135] Compare the recent attempts to draw up plans for rationing health care in Alameda County and Oregon which have made bunion treatment higher in priority than treatment to delay death in terminal illnesses, organ transplants, plastic surgery and dental care. (New York Times, March 27, 1989, p. 1.)

This type of situation, in which physicians weigh their danger of HIV-infection against the patient's benefit from the proposed treatment is a dangerous and probably unsolvable dilemma. Yet it is not clear that we want to require physicians to attempt to treat patients regardless of personal risk. Though there is some difference between bunionectomy and a hip replacement (providing a patient with a wheelchair and Tylenol with codeine are not medically comparable treatments to hip replacement by any realistic definition), allowing physicians to refuse to do either procedure means that each individual case must be weighed by each individual physician along the continuum from a duty to treat to no duty to treat. Since each physician perceives risk differently, each physician will have different ideas of when her risk outweighs the benefit to the patient. If a physician can refuse to do a procedure on this basis, when the patient has medical indications for the procedure and has consented to the procedure, patient autonomy is considerably diminished. If patient autonomy is valuable, then physicians may not be able to refuse to provide such treatment solely because they think their risk is excessive. The exception to this statement is when medical treatment is available which is comparable to the surgical treatment, and the two treatments are often used interchangeably to treat the same condition, or if the procedure is being done solely for diagnostic purposes and is arguably superfluous.

There is no one overarching model of the doctor-patient relationship which can be used as a basis for affirming either a duty to treat all AIDS patients or an absolute right to refuse to treat HIV-infected patients. The contractual model is the most commonly used model at the present time; however, the problems with this model are profound enough that we cannot base a right to refuse on it. In addition, models of the doctor-patient relationship based on the interaction of non-surgeons with their patients may be inaccurate descriptions of the way in which surgeons conceive of their responsibilities to patients. Finally, within any conception of the doctor-patient relationship there may be situations that reduce the obligation of the physician to care for the patient. These situations are difficult to delineate and if decided by individual physicians, will lead to heterogenous standards of treatment.

PART V: SOLUTIONS TO THE PROBLEM OF PHYSICIAN AVOIDANCE OF AIDS PATIENTS

The survey of the heterogenous response to AIDS treatment at a few Bay Area hospitals, the anecdotal reports of high levels of physician anxiety about treating AIDS patients, and the likelihood that access to care for AIDS patients will be limited in the near future by financial constraints,[136] if not by physician refusals to provide care, all combine to suggest that we must address the problem of physician reluctance to care for HIV-infected patients. Though categorical refusals have been rare up until now, avoidance of treating HIV-infected patients has been far more prevalent. In addition, it is hard to predict the future response of the medical profession. Initial reasons for a positive response may fade. At first, most cases of AIDS were confined to large urban hospitals, and because AIDS is a new disease, patients attracted the attention of academic physicians, infectious disease specialists, and researchers highly motivated to take part in AIDS care. However, as the disease spreads, AIDS patients will be treated by a wider number and variety of specialists and primary care physicians who may not be as motivated as the initial treating doctors have been. In addition, the increasing number of drug users with AIDS may cause more

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[136] Even if all doctors treat AIDS patients, lack of resources may limit access to care for AIDS patients. Large numbers of doctors who avoid treating AIDS patients will further compound the problems of access to care.

doctors to avoid treating AIDS patients in the future.

On the other hand, resistance to treating AIDS patients may in fact decrease over time, as AIDS care becomes a normal part of medical practice. This phenomenon has already occurred to some extent in San Francisco. Physician calls for AIDS centers at some hospital other than their own have died down, as doctors have recognized AIDS care as a mission of their own hospitals. So it is somewhat difficult to predict whether in the future we will have a lessening or an increase in physician avoidance of HIV-infected patients. We must therefore be careful about over-reacting as well as under-reacting to the phenomenon. Law making and coercive policy-making aimed at punishing individual "refusers" need to be our last resort, not our first line of defense.

A review of the literature on doctor-patient relationships, medical professionalism, and the history of physicians' responses in prior epidemics provides no clear answer to the question of whether doctors have the right to refuse to treat AIDS patients. No one model of the doctor-patient relationship corresponds to reality enough that we might derive guiding principles of behavior from it. Two competing notions of medical professionalism provide conflicting answers to the question of whether physicians have the duty to accept new AIDS patients or the right to refuse to initiate doctor-patient relationships with AIDS patients. Neither of these notions of professionalism is

either "wrong" or "right"--they have existed side by side throughout the history of the medical profession in America. Thus the profession cannot derive a right or duty from one while ignoring the existence of the other notion.

The response of Bay Area hospitals and physicians has clearly been heterogenous. Most hospitals have not compromised their access to care for HIV-infected patients, but some have. Many doctors treat a large number of HIV-infected patients, but quite a few instances of shifting of care among doctors, or not performing surgery, or providing alternative treatment rather than surgery have occurred. Some of these decisions have been medically sound; others have been more questionable.

This paper has dismissed the arguments that the risk of occupational HIV infection is low, physician fears are based solely on ignorance or prejudice, and therefore treating AIDS patients should be a normal part of medical practice. It has discounted rights and duties derived from any one model of professionalism or the doctor-patient relationship while ignoring the existence of the others, and has discounted duties based on the "tradition" of medicine. Having done so, I now suggest three further approaches to refusals to treat AIDS patients. (1) Society can appoint "AIDS doctors" and create "AIDS hospitals"; (2) society can require each physician to treat AIDS patients, or (3) society can allow doctors to decide based on their personal

judgement whether they will or will not treat AIDS patients. The first two solutions are probably unworkable; the third solution is only possible if changes are made in the way society and the profession frame the debate about AIDS care so that AIDS care is valued, physicians who provide that care are supported, and the risk from HIV is defined as a collective risk which all members of the profession should face together.

A. Creation of "AIDS Doctors" and "AIDS Hospitals"

Public health departments could create "AIDS hospitals" and "AIDS doctors" as modern "plague doctors" who take on additional risk for increased compensation. In the United States up until the twentieth century, the public health department was responsible for disease surveillance and prevention, and often for hiring physicians to work in public hospitals and clinics.[137] However, in the twentieth century, the sick poor have gradually come under the purview of graduate medical education; doctors-in-training practice their skills disproportionately on poor patients.[138] Modern

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[137] Daniel M. Fox, "The Politics of Physicians' Responsibility in Epidemics: A Note on History," Hastings Center Report April/May 1988, 20-25.

[138] This is not to suggest that the poor get inferior treatment; often University hospitals are considered the finest hospitals.

"plague doctors" have until now been the house staff of public and teaching hospitals and the faculty members associated with these hospitals. However, these doctors are not accorded special benefits or privileges. House staff are required to accept higher risk than other members of the profession for less renumeration, because the disproportionate share of work with AIDS patients falls more by default than design on house staff. Since graduate medical education has taken over the care of the poor, there are no social mechanisms for hiring specific doctors to work with infected patients during an epidemic. In this century, we have had no appointed "plague doctors" who have received financial compensation for agreeing to take on extra risk. Thus developing a system of "AIDS doctors" would require the development of new social mechanisms for recruiting and hiring individuals willing to treat AIDS patients.

Such a system of "AIDS hospitals" and "AIDS doctors" would cause a large upheaval in medical care delivery systems within a community. A full range of specialists would have to be recruited to staff such an "AIDS hospital" and its outpatient clinics, since presumably asymptomatic HIV-positive individuals would receive care at such a hospital as well as AIDS patients. No hospital is likely to volunteer to become such an AIDS center. Providing AIDS treatment is not a lucrative proposition unless reimbursement schemes are changed and research money is

funneled to such institutions. An "AIDS hospital" then would most likely have to be established as a new hospital at a time of severe budgetary constraints in the health care financing arena when numerous hospitals are closing for financial reasons.

Such a system of "AIDS doctors" would also provide no guarantee to "non-AIDS doctors" that they were not exposed to the risk of contracting HIV unless doctors routinely tested all of their patients for HIV prior to each visit. Even with routine testing, patients who had recently become infected with HIV would not test positive and therefore would still present a risk to the doctor. Thus most doctors would inevitably still be at some risk of contracting HIV occupationally. Just because the risk would be decreased does not mean that it would automatically be defined as "acceptable." In addition, "non-AIDS hospitals" would still be responsible for treating emergency patients, regardless of HIV status. Creating a system of "AIDS doctors" and "AIDS hospitals" would thus be a difficult and dislocating task with benefits that do not clearly outweigh the cost.

There is little information available upon the acceptance of "voluntary" risk as a function of wage benefits. Studies of miners exposed to high occupational risk suggest that there is an exponential relationship between wages and risk assumed such that risk is

proportional to the third power of wages.[139] Whether these findings have any relevance to the problem of physician reluctance to treat AIDS patients is unclear; would added financial incentive for treating AIDS patients induce more physicians to assume the personal risk of providing treatment?

It is also not clear that physicians are a group of workers whom society would be willing to compensate for taking on extra occupational risk. Economists tend to view occupational risks as a commodity: riskier jobs receive higher wages to compensate workers for voluntarily accepting jobs with a risk of death.[140] However, risks imposed upon the public involuntarily are typically uncompensated. Are physicians analogous to miners? Should they be compensated if they voluntarily treat AIDS patients? Or are they agents of society who must take on some personal risk without compensation? Physicians in the yellow fever epidemic were considered "public property".[141] The nature of the social

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[139]Chauncey Starr, "Social Benefit versus Technological Risk," Science 165:1232-1238.

[140] William D. Schulze, "Ethics, Economics and the Value of Safety," Societal Risk Assessment: How Safe is Safe Enough, ed. Richard Schwing and Walter Albers (New York: Plenum Press, 1980), 217. However, it is not clear that the riskiest jobs are always the most highly compensated. See Mary Douglas, Risk Acceptability According to the Social Sciences (New York: Russel Sage Foundation, 1985),10.

[141] Molly Cooke, Chair, Ethics Committee, San Francisco General Hospital. Grand Rounds, University of California, San Francisco, January 19, 1989.

contract between the medical profession and society may be such that physicians cannot be seen as "workers" who voluntarily assume risks and they would thus be ineligible for wage benefits. It is unclear then whether society would be willing to compensate doctors for assuming increased risk of contracting AIDS occupationally.

B. Imposition of a Duty to Treat on Every Physician

A second solution would be for the society, through licensure mechanisms, or the medical profession, through hospital privileges, to impose a duty on every physician to treat all AIDS patients seeking the physician's services. To obtain a license to practice in California or to obtain privileges at any hospital a physician would have to pledge to treat HIV-infected patients with problems within her realm of competence. If a physician refused to treat an AIDS patient, her license or hospital privileges could be revoked.

Such a system seems to me only a solution of last resort. We have seen in the examples given by Dr. Day and others the difficulty of deciding whether a refusal to provide care to an HIV-infected person is medically justified or is based solely on HIV seropositivity. Reviewing instances in which treatment for an HIV-infected patient was changed or was not initiated would be a

difficult enterprise. Since the sanction would be so great for an instance of refusing to treat, reviewers would likely be hesitant to decide that refusal based on seropositivity had occurred except in the most glaring (and therefore quite rare) cases.

In addition, do we really want to impose the burden of treatment on every physician? Suppose a physician has all the patients she can handle in her practice (although she has fewer than her colleague next door) when an HIV-infected patient comes to her for treatment? Will she be required to take on this additional patient just because he is HIV-positive? Suppose one of two partners in an office specializes in counseling patients who have received a positive HIV test? Do we penalize the partner who does not see these patients?

Such a duty to treat would be very hard to enforce and would have the potential to be extremely coercive. It would require review of individual doctor's practices and of many cases in which a clear line between medical and seropositivity reasons for treatment changes would be very difficult to draw. It thus seems only plausible as a solution if widespread problems of access to care for AIDS patients occur due to physician refusals to care for them.

C. Voluntary System of Treatment

Finally, a voluntary system would allow individual physicians to decide whether or not they will treat AIDS patients. This system is only possible if the profession takes steps to define itself as a community, to emphasize doctor's obligations to one another, and to shift the focus of the debate about AIDS treatment away from discussions of "reasonable" risk. At the same time, the society must begin to change the pervasive stigma of AIDS, and to value both patients with AIDS and the doctors who care for them. If the profession and the society do not take these steps, a voluntary system is only possible if society is willing to live with the possibility of denying care to AIDS patients.

A voluntary system is only an acceptable approach to the provision of AIDS care if the profession expects few physicians to avoid treating AIDS patients. If widespread avoidance and refusal to care occur, such a system is no longer acceptable for a number of reasons. First, to be refused treatment by a physician, particularly if one has had a long term relationship with that physician, is an insult. It further stigmatizes an already stigmatized individual. Refusing to treat a patient diminishes the patient's dignity and autonomy. The values of patient autonomy and personal dignity will not be given up so easily by our society. Delay is also inherent in a system of referrals; these delays might cause medical harm to these patients.

Another problem with a voluntary system in which widespread avoidance of AIDS patients occurs is that as fewer doctors provide the bulk of the AIDS care, these doctors are likely to reach a point at which they refuse to treat more AIDS patients (or simply do not have any time to treat any more patients) because they find the additional risk they are taking unacceptable. Thus refusals to treat AIDS patients might snowball in such a system.

Finally, I do not think it tenable to argue that the medical profession can turn away from HIV-positive patients, and thus a voluntary system in which many physicians refuse to provide AIDS care would no longer be an acceptable solution. The medical profession does have a contract with society.[142] Physicians owe some debt to their community, based on the gift of their training and the status which the community has bestowed upon them.[143] In return for their provision of a public service, the community allows physicians to practice with little competition from other healers. Patients from the community are subjects for teaching in training, and allow themselves to be treated by novice doctors or doctors-in-training. Accepting these benefits entails a social requirement, that of treating the

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

[143] William May, The Physician's Covenant: Images of the Healer in Medical Ethics (Philadelphia: The Westminster Press, 1983), 102.

sick. I have heard of no doctor, even those who have refused to treat HIV-infected patients, who has argued that the medical profession as a whole does not have the responsibility of providing medical care to AIDS patients.

However, a voluntary solution is the most workable solution if the vast majority of doctors treat AIDS patients. To assure that widespread refusals to treat do not occur, and therefore necessitate legislation or hospital policy formation requiring that physicians treat in order to be licenced or given hospital privileges, the profession and the society must address the pervasive and problematic issues of physicians' fears of contracting AIDS occupationally. Refusal to treat AIDS patients is only the extreme response on a scale of responses to treating AIDS patients based on fear. We must address the entire range of responses by attempting to decrease physicians' fears. Fear not only compromises patient care, but takes a toll on doctors as well. Though clearly complex social and ideological issues may be involved in the genesis of this fear, the fact remains that most physicians define their emotional attitude toward treating patients with HIV as fear. It seems practical and useful then to accept this definition of the response of physicians and aim social attempts to cope with the problem of physician avoidance of AIDS patients at diminishing the fear.

The way in which occupational acquisition of HIV has

been defined as a risk has given rise to the whole spectrum of physician behaviors surrounding AIDS treatment. By focusing our efforts on understanding how this risk is defined and perceived, by abandoning much of the rhetoric of the debate about physicians' obligations to AIDS patients to date, and by defining the medical profession as a community that supports and values AIDS care, we are likely to decrease problems along the whole spectrum of behaviors concerning AIDS treatment, from treatment with fear and trembling to outright refusal to treat.

The phenomenon of refusals to treat AIDS patients highlights a difference between defining and facing risk as an individual and doing so as a community. How the medical profession defines itself, as a group of individuals, or as a community facing a shared risk will decide how the risk from HIV is perceived, and the kinds of responses to treating patients individual doctors adopt. To continue to provide medical care to HIV-infected patients, the medical profession must take steps to define itself as a community, a community which supports its members, which cares about its members, and in which all members are committed to facing a real risk together. Treating an AIDS patient is not a personal issue, but a form of collective action. If this kind of definition prevails, the need for regulation of individual physicians' behavior is likely to decrease, because the fear of HIV may lessen and reluctance to treat

HIV-infected patients may dwindle. If the profession takes no steps to define itself as a community with a shared mission of providing AIDS care in the face of occupational risk of HIV infection, then deciding how and whether to face this risk will be up to the individual. Heterogeneous responses will then be inevitable. Fear of AIDS will be unlikely to abate, and if access to care becomes compromised, as it likely will, society may impose coercive regulation on individual physicians.

There are a number of ways in which the medical profession can define itself as a community. The first is to acknowledge fear of HIV transmission as a "legitimate" fear based on some real risk. We must abandon the rhetoric of "irrational" fears. Acknowledging that physician fears are real and are justified will help physicians feel more supported and less persecuted, and this step alone may reduce the perception of risk. If we can define the problem without resorting to defining it as a case of "unethical" doctors with "irrational" fears "discriminating" against patients, doctors are more likely to listen to the solutions proposed. This is not to say that homophobia, lack of caring for drug abusers, or distorted ideas about contagion do not exist. They most certainly do, and they are part of the phenomenon. But they are not the only reason that physicians may avoid treating HIV-infected patients. By labeling physicians who are fearful of HIV

infection, but nevertheless treat patients, as irrational or prejudiced because they are fearful is likely just to make them more reluctant to treat rather than less so. They need to feel support from their community that their actions are courageous and are applauded if we hope to get them to continue to treat AIDS patients.

Being a member of the medical profession should include a sense of commitment to other members of the profession. The medical community is a closed community; refusing to take any personal risk necessarily increases a colleague's risk. How can a member of a small surgical department watch his colleagues take on extra risk so that he may remain risk-free? What impact does such an environment have on collegial relationships? Individual doctors must understand that their refusal to accept personal risk places other members of the profession at increased risk. The medical profession is not going to have the luxury of hoping that there will be enough personnel "out there" who are willing to treat HIV-infected patients. The neglected obligation in the Hippocratic Oath to teachers and colleagues must be revitalized.[144] Doctors depend on one another for referrals, collaboration and consultation. They are thus interdependent. Physicians do not practice solely as individuals; they owe their colleagues the courtesy of not

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[144] Ibid.

requiring them to shoulder an excess burden of the risk from HIV. For example, the risks to any one individual doctor at a community hospital could be lessened if private hospitals took on more of the burden of caring for HIV-infected patients, particularly indigent patients then they have to date. Though the medical profession as a whole has an obligation to treat AIDS patients, it does not follow that some physicians must take on disproportionate risks of contracting AIDS.

The medical profession as a whole must decide whether there are any conditions under which a doctor's refusal to treat HIV-infected patients might be legitimate. For instance, an immunocompromised physician might be allowed to categorically refuse to treat HIV-infected patients. And medical students (and nurses and technicians) who do not yet feel comfortable with their blood drawing skills might also be excused from doing blood work on HIV-positive patients until their skills improve.

The profession is responsible also for warning potential future members of the profession that medicine is not a risk-free profession. Applications to medical school should contain a section detailing the occupational risks of HIV and other infections. Applicants for residencies should expect realistic estimates of their exposure to HIV-infected patients when they apply for residency in a particular hospital so that they understand how much AIDS care will be

expected of them at that particular hospital.

Hospital administrations must also realize that "personal compassion toward AIDS patients, particularly by individual health care workers, can only exist and be maintained within a framework of confidence in a system that provides both the necessary resources and an appropriate environment for such care."[145] All hospitals must provide access to care for AIDS patients. In addition, hospitals have the duty to provide as safe an environment as possible for their employees. There is simply no excuse for not providing health care workers ready access to the supplies that reduce the risk of occupational HIV transmission. Hospitals must make sure supplies are available--"it's on back order" is simply an unacceptable answer. A physician who cannot find the supplies she needs to treat a patient safely is justified in refusing to provide the care.

The society could also increase physicians' sense of being cared for and valued by their community if research dollars were supplied for research into technologies to reduce the chances of needlesticks and other blood exposures. Many of these measures could be relatively simple. For example, the most widely stocked intravenous catheters spill blood onto the hand of the person inserting the catheter when the vein is pierced. Another brand exists

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[145] Gerald Friedland, "AIDS and Compassion," Journal of the American Medical Association 259(19):2898-2899.

which encloses the blood in tubing so that it will not spill on the person inserting it. Why isn't this brand the standard brand of intravenous catheter?

Hospitals must provide education about infection control *and* the risk of HIV transmission. This education will be more effective if such programs take into account the ways in which people perceive risk. Thus people who design the educational programs must be sensitive to the rhetoric they use, and the way they frame the issue. They must allow health care workers to vent their own experiences with HIV exposure in order to deal with the workings of individual risk perception.

A worker who is exposed to HIV-infected blood should be able to expect institutional support, counseling and follow-up. She should also be covered by disability insurance which reflects her income (or in the case of a house officer her potential income). Workers' compensation does not now approach a reasonable level of compensation for doctors who contract HIV in the workplace.

Experts in infection control may have to release their hold on some information and power in order to give individual physicians a sense of empowerment.[146] Individuals need to feel some control over their practice environment. Thus perhaps physicians should not be told that they

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[146] Dr. Peter Jensen, Chief, Infectious Disease Clinic, San Francisco Veterans Administration Hospital.

"cannot" test patients for HIV. If strict informed consent guidelines are followed, and confidentiality is assured, allowing individual physicians to test for HIV may be acceptable when they feel it will change the technical methods they use in order to increase their own safety. The San Francisco Veterans Hospital provides a model of how such a program might work. Physicians may test for HIV as long as a witnessed informed consent form is attached to the blood specimen when it is sent to the lab. Testing may be done at alternate test sites if the patient does not want the result to become part of the medical record. The hospital is setting up a central counseling consultation service which will offer physicians guidance in how to counsel patients after an HIV test. This system seems an acceptable compromise which safeguards the confidentiality and autonomy rights of the patient, while allowing the physician to feel empowered to take steps which she feels will reduce her risk.

If a hospital takes the steps to assure that its policies support physicians in providing care for AIDS patients, if the hospital consistently provides its employees with the equipment they need to protect themselves from exposure to HIV, and if the hospital defines AIDS care as a valued part of its mission, then the hospital is justified in expecting its physicians to be willing to treat AIDS patients. Though hopefully such measures will make any

regulations requiring such care unnecessary, if such regulations are still necessary, a hospital that has taken all of the above steps is justified in requiring all of its employees to assume some part of the care of AIDS patients at that hospital.

If the professional community begins to value AIDS care, to support doctors who provide the care, and make sure that they are provided with every means available to reduce their risk, doctors will feel a part of a community that is sharing a risk. Their sense of isolation will decrease; their sense of control will increase, and they will be less likely to fear contracting AIDS occupationally. As their fear decreases, physicians who have avoided treating AIDS patients may begin to take on their share of AIDS treatment. These measures alone thus may be all that is needed to assure that adequate numbers of physicians are available to treat AIDS patients.

If the society expects certain of its members (e.g. physicians) to provide access to medical care to patients even at personal risk, the society also has the obligation to provide access to medical care for all patients. Society should not ask more of its doctors than it does of itself.

Clearly, this society has yet to make such a commitment to universal access to care. During the last decade, federal and state governments have continually cut funding for Medicaid and for medically indigent adults. In 1975 63%

of the poor were eligible for Medicaid, but in 1983, less than 50% of people below the poverty line were eligible for Medicaid.[147] At the same time, the California State government transferred responsibility for "medically indigent adults" back to the counties at 70% of the previous funding level. These funding cuts were one of the reasons numerous county hospitals--which provide a disproportionate share of care to the poor--closed during the last decade. California has 58 counties, but only 24 open county hospitals.[148]

Many HIV-infected individuals are members of the poorer classes in our society and a large proportion of AIDS patients either start out on Medicaid or are forced to go on Medicaid after exhausting their own financial resources. The number of AIDS patients who are poor will only increase in the future as AIDS disproportionately affects the poorer members of society. Compensation for treating patients on Medicaid has been cut to the point that in some specialties the payment doesn't even cover overhead. If society is going to require physicians to treat a certain number of HIV-infected patients, it must make doing so not lucrative, but financially viable.

It is also only at the broad social level that we can

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[147] Health policy class notes, Summer 1986.

[148] Ibid.

hope to change some of the pervasive metaphors of AIDS which contribute to the way in which physicians perceive risk. Only the society as a whole can begin to treat AIDS victims with more compassion, so that a diagnosis of HIV infection is not a socially stigmatizing event. The society must value individuals who provide care for HIV-infected patients; it must recognize this as a courageous and virtuous act.Only then will individuals faced with the risk of occupational HIV infection be able to face that risk with the knowledge that if by some chance they do contract the infection they will be hailed as heroes rather than ostracized. This shift of attitude would do much to reduce the fear of occupational infection.

To decide with what attitude she is going to treat a patient who presents a personal risk, each individual doctor must wrestle with her own fears and senses of duty to herself, her family, and to her other patients. No decree by society or by the medical profession can make an individual doctor courageous, virtuous or unafraid in rendering care. No decree by society can make doctors act with compassion, understanding and warmth toward their patients with AIDS.

Providing care to HIV-infected patients is a matter both of professional morality and of personal morality. Each individual must wrestle with what a "good" person would do in this situation. The way in which a doctor treats an HIV-infected patient--with compassionate, supportive care or

with cold technicality--is a matter of individual conscience. The decision to treat is a matter of professional morality; the decision about whether care will be compassionate or distant and cold is a matter of individual conscience.

Fear of legal and professional sanctions might make individual physicians treat HIV-infected patients, but patients are likely to suffer from the cold and resentful care of doctors who do not wish to be coerced into treating AIDS patients. Sanctions cannot make physicians compassionate and respectful doctors. We can only hope that the majority of individual doctors can find the courage and sense of professional responsibility within themselves to render compassionate and respectful care to patients infected with the AIDS virus. Individual acts of compassion are only possible within a social and institutional structure that makes such acts possible.[149] Thus, if we devalue people with AIDS, if we send the message that AIDS care is a duty, but provide no support for those performing this service, we cannot expect individual acts of compassion to occur. If we build a social and professional structure that values, supports, and rewards AIDS care, we may expect compassionate care for HIV-infected patients to flourish.

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[149] Gerald Friedland, "AIDS and Compassion," Journal of the American Medical Association 259(19):2898-2899.

APPENDIX

Information about Bay Area hospitals was obtained in interviews with physicians and/or nurses at San Francisco General Hospital, San Francisco Veterans Administration Hospital, Samuel Merritt and Peralta Hospitals, Alta Bates-Herrick Hospital, and Kaiser-Permanente Medical Center, San Francisco. I conducted all interviews using the following schedule of questions. However, some sources did not know the information requested in certain questions, or did not wish to answer specific questions, so this information is not included in the discussion of that hospital.

1. What is your position at this hospital?

2. May I use your answers in my thesis and attribute them to you? [If not] - may I use them without attribution? May I identify this hospital by name? May I include anecdotes if I don't attribute them to you or use any personal names?

3. What is the average total inpatient and outpatient population at your hospital?

4. How many AIDS patients on average receive treatment at your hospital on an inpatient and outpatient basis? Is the population primarily gay men or drug abusers? Are most

medically indigent or covered by insurance?

5. Do you personally feel that fear of contracting HIV infection from patients is prevalent among doctors at your hospital?

6. Has your hospital developed a policy regarding treatment of AIDS patients? If so, what is this policy? (If no, go to #11)

7. When was this policy developed? When was the need for such a policy first felt? Why did the medical staff feel it was needed?

8. Is it a written policy? Verbal policy? An understanding? If written, may I have a copy? Has it been accepted by the doctors at this hospital?

9. Who was involved in developing this policy? Were they a formal committee? Have some or all of these people been involved in formulating other hospital policies? Which policies?

10. Do you feel that the appropriate people made the policy? Who are the people charged with implementing it? Are they the appropriate people to do so? Does the policy

contain any sanctions for those who do not follow it?

11. What are the contractual obligations between the hospital and different members of the medical staff (e.g. attendings, housestaff, other arrangements?). Is the policy designed to cover all of these different arrangements?

12. (If hospital does not have a policy) --Have there been any formal or informal discussions about the issue of treating AIDS patients?

13. Who has participated in these discussions? Is there a difference of opinion about treating AIDS patients among individual doctors at this hospital?

14. If your hospital adopted a policy about treating AIDS patients, who do you think should be in charge of formulating the policy? Who should implement it? Should the policy include sanctions for those who do not follow it?

15. Do you personally know of any cases in which overt refusal to treat AIDS patients has occurred at your hospital? Can you describe the circumstances of these refusals (e.g. in what department, what kind of treatment was refused)?

16. What was the reaction of other staff members to this incident?

17. How do you personally feel about the ethics of refusing to treat a patient with HIV infection?

18. How do you personally feel about the ethics of forcing other doctors to treat HIV-infected patients?

19. Do you personally feel that AIDS patients have adequate access to care at your institution, on both an inpatient and outpatient basis? If they do not, do you feel that their access has been compromised by overt refusals to treat AIDS patients? If not, why is their access to care limited?

20. Do you believe that access to care for AIDS patients at your hospital is likely to become a problem in the near future? If so, do you think access will be compromised by overt refusals or by other means?

21. Does your hospital have any education programs about infection control, and/or counseling and education for those workers who sustain an exposure to HIV?

22. Does your hospital ever test individuals for HIV? Does it ever test without their consent?

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