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## The Role of Nurses in the HIV Epidemic

**W**e bring to the writing of this chapter the premise that nursing and nurses are an integral and indispensable part of the health care delivery system, in particular of the HIV/AIDS care system. Critical issues facing nurses in this epidemic are the political challenges in maintaining quality of care, access to health care, and treatment and safety for providers.

We are not academicians nor are we researchers. We are two nurses, each with 10 years of experience in the HIV epidemic. We have noted the resounding absence of nurses' voices in chronicling the epidemic, yet we know that nurses have had a profound effect on the system within which we work. On a personal level, AIDS has changed nursing and each of us who has experienced its ravages in fundamental ways.

Our work experience has been in the San Francisco Bay Area, where the epidemic has predominantly affected gay men. We have worked primarily within the public and nonprofit health care system, and our patients have often been poor, homeless, and with few or no resources. We met in 1983 working on the AIDS ward at San Francisco General Hospital, the first inpatient AIDS ward in the United States.

When we undertook the writing of this chapter, we called a gathering of our peers to get feedback on the issues. Since we are both women and lesbians, and therefore prone to such egalitarian activities, we chose to throw a dinner and invite about 25 of our colleagues from various backgrounds to brainstorm with us. The group was representative of the variety of roles nurses play in the full spectrum of HIV care. It was inspiring to be in a room full of nurses who choose to work with people with AIDS.

Nurses work in all areas of the health care delivery system: in hospitals, home care, hospices, clinics, street outreach, public health nursing, education, administration, and management. Nurses work as program directors for community-based HIV programs and as managers in private organizations. Nurses' educational levels and job descriptions range from certified nursing attendants or aides to nurse practitioners or clinical nurse specialists, licensed vocational nurses and registered nurses. However, there are only

two overarching categories: nurses who do "hands-on care" and nurses who "don't do that any more but did."

The distinction between these two categories parallels that in other fields between direct service providers and administrators; for example, the differences between teachers and school administrators who were at one time classroom teachers themselves. For nurses, this is the distinction between the bedside nurse and other nurses classified as supervisors, managers, or administrators. It is a complex and frustrating relationship, one often focused on the allocation of scarce resources.

The bedside nurse is directly involved with meeting the needs of and advocating for very sick people. Nurses who aren't at the bedside are responsible for supporting the systems that support the patient care environment: personnel management, quality assurance, fund raising, safety, budgeting, and responding to the myriad state and federal regulatory agencies that define our health care system.

The consensus of the dinner group was that, overall, nurses have had a positive impact on the health care system's ability to care for people with HIV/AIDS. Although nurses have been among the many health care providers who have responded with fear and paranoia to this epidemic, and have been guilty of refusing to care for patients with HIV disease, we have also been among its most invisible and unrecognized champions. Many of the caregiving systems and units that evolved to meet the needs of people with AIDS were created by nurses and to this day are "nurse-driven." As a result, the entire structure of health care delivery has been transformed.

Nurses have always known that this is not work for the "lone ranger" practitioner. This is work best done with a multidisciplinary team. The physical and emotional demands are such that nurses working together with other professionals (physicians, social workers, counselors, psychiatrists, rehab therapists, nutritionists) will serve patients most effectively.

Our focus in this chapter is on the nursing experience of hands-on care. The physical, emotional, and spiritual aspects of that experience form a strong bond among all nurses in HIV care. The memories of those experiences remain fresh.

Nurses who work directly with patients represent the greater number of us in the profession. For a very long time, 80 percent were working in hospitals. That figure has changed as the health care system has changed, so that now the majority of us work outside of hospitals: in clinics, hospices, and home health care. We do hands-on care outside of the hospital setting.

Nurses' unique perspective has grown from our constant and historical presence in all the different places within the health care system. We are at the sides of patients who benefit from the most sophisticated technology available, as well as those individuals who are the most alienated and compromised by the system's inefficiencies and inequities.

As a disease, AIDS has challenged our health care system to expand the definition of what it means to meet the needs of sick people. Nurses have been a critical voice in redefining those needs. Not only hospital and medical care, but housing, meals, transportation, legal assistance, and help with the activities of daily living must be included. The need for the full continuum of care has been dramatically revealed as the epidemic moves into communities of color and other populations where access to health care has been marginal at best. Nurses have served as important links in that continuum, providing services in nonhospital settings within communities.

Despite all of this presence, we have been traditionally and historically invisible. Nursing is a profession that is overwhelmingly female, greater than 90 percent. In the shadow of male physicians, female nurses have been portrayed as handmaidens. Women in our dinner group could recall being instructed to give up their chairs at the hospital nursing station when a doctor approached.

The challenge to nursing reflects the challenges faced by women in a sexist society. In the field of AIDS, there are now many male nurses, primarily gay men, working alongside female coworkers, both heterosexual and lesbian. Sometimes our motivation for being in this field, as women, has been called into question by our gay colleagues. They have been suspicious of our ability to truly care, since they perceive that we have not been truly affected by AIDS. Lesbians have been "grandmothered" into the "truly caring" circle because, they feel, we probably know what homophobia is about. However, the motivations of heterosexual women caring for gay men are often suspect.

Although many female nurses, heterosexual and lesbian, have commented on the relief they experience working in an environment where their gay male patients don't come on to them, garden-variety sexism remains alive and well. As recently as a few years ago, a male patient asked one of us as we arrived in his room, "Are you my waitress for today?" And one of the nurse practitioners in our group was asked in 1993, "Can ladies be doctors here?"

We have been put in our place by other healthcare professionals who see us as second class providers, charged with caring for bodily functions. The irony is that we are trusted with the most intimate and complex procedures, but not with long-term strategic planning or budgetary decisions.

Nurses can muster great influence in many settings, but we have little real authority. Despite the inherent sexism built into our status as professionals, the AIDS epidemic has attracted many nurses motivated by longstanding traditions of fighting for social justice and equality. These nurses stepped forward just as many in our profession were refusing to care for people with AIDS and embraced two socially disenfranchised populations: gay men and injection drug users. This combination has fueled an intensely political environment which in itself is attractive to many who want to grapple with the relationship between science and politics.

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## THE POLITICS OF HIV NURSING

As health care providers, we have a sorrowful legacy to overcome: that of working in an industry that has historically failed to serve gay men, lesbians, women, addicts, poor people, and people of color. Because of the demographics of the AIDS epidemic in the United States, these forces are played out in daily dramas at the bedside, in clinic waiting rooms, and in management meetings.

As health care workers, we have to cope with how we have internalized this legacy. In the play *Miss Evers' Boys*, by David Feldshuh, the public health nurse employed by the infamous Tuskegee syphilis experiment vividly epitomizes the catch-22 in which nurses have found themselves for years. This government-funded study was designed to follow the course of untreated syphilis among African-American men in the South. It began in 1932 and continued long after the discovery of penicillin in the 1940s. The play focuses on an African-American public health nurse who was the ultimate foot soldier in this despicable experiment. The play portrays the nurse's agony as she listens to her patients, their hopes for treatment and cure, knowing all the while that her efforts to advocate on their behalf are futile. Her physician supervisors, determined to sacrifice the patients in the interest of "scientific knowledge," withheld treatment in order to study the natural course of the disease to its end point—death. Without her complicity, the experiment would have failed. She was the crucial link between the physician-researchers and the "research subjects."

In the struggle to find effective treatment for HIV infection, clinical trials for experimental drugs were initially available only to a select group of participants. Women and people of color were not included in these studies for many years. Nurses, patients, and AIDS activists publicly pressured the pharmaceutical companies and research institutes. The deeply conservative traditions of research were debated, challenged, and changed by this public examination. Because of these efforts, drug studies are now more open, access to treatment has increased, and activists and patients are invited to give input to the actual study designs.

Nurses have been increasingly affected by the poverty connected with this disease. Last year, a nurse who had been working on the AIDS ward at San Francisco General Hospital for over eight years expressed this vividly when he commented, "We used to be seen as little angels of mercy. What happened? Our patients all seem to hate us." An adversarial or frustrating relationship is what we often experience. Patients frequently come into the health care system with distrust bred by years of neglect and abuse. Accustomed to being treated with condescension and disrespect, they respond with hostility to mask the fear and apprehension that once again they will not be cared for. They come with no feeling of empowerment, no training in advocacy or experience to negotiate their way through the health

care morass. They run into nurses (and other health care providers) who themselves lack the training, skills, and understanding to overcome these historical legacies. As one nurse crudely put it, "It's not as fun anymore."

The problems patients are facing often go far beyond HIV disease. When a patient is homeless, no amount of tender loving care on the part of a committed and dedicated nurse will be able to change that fact. Instead, the nurse is seen as an accomplice to an unjust system that allows people with terminal diseases to be discharged to homeless shelters and addicts to go untreated for their addiction while receiving the latest and most expensive AIDS drugs. Nurses must learn to cope with these contradictions and not simply internalize the frustration and anger they feel.

As other fields began shrinking as the result of massive health care and social service cutbacks of the 1980s, the "AIDS industrial complex" was spawning new jobs and programs with funds that were wrestled from the federal government to combat the growing epidemic.

The field of AIDS has generated many high-paying jobs and career opportunities. A few years ago, while attending a national AIDS conference, reflecting on the careerism and grandstanding we encountered (and after one too many cups of coffee), we named the phenomenon we observed APES (AIDS provider ego syndrome). We were not immune to what happened in other fields of medicine. We witnessed the rapid professionalization of AIDS. The agencies spawned by early responses of community-based agencies were being replaced with traditional medical model approaches to care. Sadly, and somewhat cynically, we noted the changes.

The grassroots movement of the early 1980s was becoming part of the medical industrial machine. There was money to be made on the HIV epidemic, and the health care and research industries were gearing up. The traditional roles of doctor, nurse, and patient were revived and renewed. Many women wonder, if similar job opportunities existed in the field of women's health (if there were a better-financed response to the epidemic of breast cancer), how many of us would be there instead?

Lesbians and gay men emerged at the forefront of nurses willing to take on the assignments of caring for people with AIDS. By "seizing the moment," these nurses provided necessary role modeling and risk taking (long before much of what we know today about HIV) for health care workers in general. To this day, the proportion of lesbians and gay men in AIDS nursing is high. For many people, the epidemic has provided their first opportunity to be "out" on the job. In fact, being lesbian or gay sometimes added value and credibility to our professional status. Nurses with a personal background and experience with the challenge of recovery from drug and alcohol addiction were being sought out. How ironic that to be gay, lesbian, or an ex-junkie could actually make you more marketable in the AIDS workforce! However, lest we become delusional, the glass ceiling is as thick and strong in AIDS as elsewhere. Very few of the AIDS health care leaders on the



national scene are other than white, heterosexual men, primarily physicians. In 1993 Kristine Gebbie, a nurse, was appointed by President Clinton to be the "AIDS czar," but she had no real power and no budget.

Beginning in the late 1980s, political battles were being waged on the streets. ACT-UP and other AIDS activists demonstrated before the giant pharmaceutical companies and outside the CDC and the FDA (later, they would move inside). Quieter and more personal battles were taking place in the corridors of clinics and hospital wards. Nurses were often the central characters in these dramas. At stake was a revolutionary redefinition of the role that patients (otherwise known as clients and consumers) were to play in the course of their illness. "ACT UP, FIGHT BACK!" became the battle cry. From treatment choices, to how aggressively they wanted to be treated, to opting for stopping treatment altogether and choosing the time and place of their death, gay male patients were negotiating a new relationship with their physicians and nurses. These men helped create a new standard and awareness among all consumers of health care. Their contributions will forever change the way victims become activists.

The impact on nurses' roles has been profound. Schooled in their role as "patients' advocates," nurses had to be willing to suspend judgment and their own opinions and feelings to become partners with their patients, and with their patients' lovers and families, in battling not only HIV disease but also unresponsive and archaic institutions. New concepts, such as "patient-centered care," were piloted on hospital AIDS wards.

The AIDS epidemic changed a lot of definitions and assumptions. In more progressive health care settings, old policies that restricted access to hospitalized patients were thrown out. The patient became the ultimate definer of his or her reality: Who constitutes the "family"? Who is the next of kin? Who will participate in decisions about the course of the illness? Who gets to spend the night with a dying patient? And, for many nurses, the newest challenge (as members of transsexual and transgender communities are becoming ill): Who gets to define the gender identity of the patient?

For every nurse in this epidemic willing to listen to her or his patient, be the voice that couldn't be heard, or argue with a team of doctors with long white coats, we can see a health care system that becomes more patient focused rather than physician dominated. Policies can become responsive to human needs; new standards can emerge to help change performance; and ultimately, the patient receives better care. Nurses celebrated these innovations and enjoyed some credit for their creation.

## THE RISKS OF OCCUPATIONAL EXPOSURE

While we were basking in the excitement of our new sense of empowerment and accomplishment, we lived and worked in denial about any possible risk to ourselves.

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In 1987, a nurse at San Francisco General Hospital became HIV-positive following a needlestick she had sustained six weeks earlier. The news sent shockwaves through the hospital staff and the entire community. For four years, the focused energy had been on convincing the world that working in this field was safe and the risk of exposure minimal. Nurses compared their record of needlesticks almost as trophies, and each new exposure became proof that concerns and fears among health care workers were mere AIDS hysteria.

The nurse, known as Jane Doe, waged a lonely and difficult battle with the San Francisco city bureaucracy to retain anonymity and collect workers' compensation for her medical expenses. Protecting her privacy and future employment proved to be an exhausting and lengthy struggle. It wasn't until nearly two years later, after a nurses' union intervened, that the city relented and agreed to set up procedures that would allow her to maintain confidentiality.

The risks to nursing personnel were not taken seriously. Action was not swift. To protect the workers meant acknowledging it was real. It would take three years before the hospital moved dirty needle disposal boxes out of the patients' bathrooms to the bedside, thereby reducing the risks that nurses and others would have of sustaining a needlestick like Jane Doe's.

Jane Doe led us to break with denial. We lacked any conscious realization of the relative risk involved in occupational exposure to HIV. The fact was that little was being done at the national level to assist health care workers with occupational risk. We expected our health institutions to take care of us. Through informal networks we heard about nurses in other parts of the country who had become HIV-positive through the actions or negligence of others. We felt frightened, outraged, and appalled—after all, we were only doing our jobs.

Many of our colleagues believe that there is underreporting of occupationally acquired HIV infection. In the San Francisco Bay Area alone, we have heard of no less than 10 nurses becoming HIV infected on the job. However, if a nurse belongs to any of the recognized "risk groups" for HIV and is infected on the job, the chances of being recognized and compensated for an occupational exposure are practically nil. The case reporting and definitions are rigid and limited.

In the United States, there are 100,000 reported needlesticks per year. If we use the current seroprevalence data of 2 percent HIV-positivity in the patient population, that means that 2,000 of the needlesticks are from HIV-positive sources. At the current rate of seroconversion of 0.03 percent, the result would be 8 health care workers becoming HIV-positive each year.

The CDC has reported 12 nurses with "documented on-the-job transmission" in 10 years. Another 14 nurses are classified as "possible" on the job transmission. The criteria set by the CDC to be classified as a "documented exposure" is so rigorous that few pass the test. In addition, there is

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considerable nonreporting due to a realistic fear that confidentiality and privacy will not be maintained. The experience of our patients demonstrated all too clearly the unfortunate results when health benefits or employment are endangered.

Many in our profession are critical of the poor response and lack of leadership from our federal health agencies with regard to occupational exposure. Nurse Jane Doe expressed outrage when she compared the CDC's handling of health care worker occupational exposure risk to their handling of the possible HIV transmission from a dentist to six patients in Florida.

In 1990, Kimberly Bergalis became nationally known as an "innocent victim." She advocated for mandatory testing of health care workers and mandatory reporting of HIV-infected health care workers. The CDC did little to lead the public out of its mass hysteria and counter the ravings of a few men on the congressional floor. Longstanding advocates of mandatory testing and reporting (under the predictable leadership of Senator Jesse Helms of North Carolina) were in charge of the Senate hearings on this subject. The CDC's willingness to release information and speculate as to how transmission took place in the Bergalis case (which to this day is still in dispute) came as an insult to all of us in the profession who believe the CDC consistently underreports the number of health care workers infected on the job. An added concern may be that many health care workers would be unwilling to work with patients with AIDS if honest information about rates of on-the-job transmission were regularly released.

The final straw came in the summer of 1991 when the Senate voted 99 to 1 to force states to adopt CDC recommendations that included a policy of "voluntary" disclosure of HIV status by health care workers to their patients. The impact on nurses was profound: when had the Senate voted 99 to 1 at any time and for anything in the history of this epidemic? Where was the leadership to inform the public of where the real risks were? In fact, once all the posturing was done and both Dr. Acer (the Florida dentist) and Kimberly Bergalis (his patient) were buried, after the news media had long lost interest in the story, the CDC changed its position and began to reassert that the risk posed by HIV-positive health care workers to their patients was minimal. No other case such as Dr. Acer's has ever been reported.

Jane Doe is struck by the irony that, in pregnancy, the risk to women over 35 of having a Down's syndrome baby is 1 in 1,000. As a result, the community standard is to recommend amniocentesis to all pregnant women over 35. Occupational exposure via needlesticks, resulting in seroconversion, is three times greater a risk (3 in 1,000). Why is there not a national standard mandating that all steps be taken to protect health care workers and accurately track the incidence and circumstances of seroconversion? Other threats to health care workers exist: hepatitis B and C, cytomegalovirus, and repeated exposure to toxic chemotherapeutic agents, to name a few.

Given the longstanding tradition in health care of discouraging workers

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from lobbying for a safer workplace, and the economics involved in investing in new, safer technologies, there is little material incentive for the health industry to make an honest reckoning with what is happening to its providers.

New and safer equipment (“needleless” syringes and IV access, better masks and improved gloves) is often priced at many times the cost of the traditional low-bid equipment in general use. As profits have begun to shrink throughout the health care industry, purchasing newer, safer, more expensive equipment seems less likely.

### “NOTHING HAS GIVEN ME THE SATISFACTION THAT AIDS NURSING HAS”

Despite the risks of occupational exposure, we know of few nurses who have left this field of work once they start. So what is it that keeps so many of us working with people with HIV/AIDS?

In our caregiving to HIV/AIDS patients, we have experienced the most extreme highs and lows our profession has to offer. The compelling, exhausting, fulfilling emotional nature of the work has kept us here. The exposure to gay men’s sensibilities and humor, the richness of how all the many cultures approach illness and death, the incredible grace and intimacy we have shared with our patients have kept us here. Our nearness to the mysteries of life and transitions to death has kept us here. We put up with low status, long hours, physically demanding work, and oceans of diarrhea in exchange for those moments we experience as packed with meaning.

On a day-to-day basis, we are not dealing with the overwhelming nature of an epidemic. It is the individual who is sick. In the face of tremendous loss and grief, we believe we can alleviate some of the suffering of those who are ill, by what we have to offer in the simplest way: by touching them. Nurses spend time touching people, bathing, drying, massaging, shampooing, combing, dressing, and feeding. We also spend time poking and prodding patients, preparing them for procedures in which perhaps neither the patient nor the nurse has any faith.

Outside of hospitals, nurses spend time arranging and coordinating care for patients. We lobby insurance carriers to pay for needed care that may technically be outside of a patient’s benefit, but is clearly cost-effective. Coordinating volunteers and others to provide rides, meals, and assistance are tasks that offer tremendous satisfaction to the nurse and relief for a client whom science has little to offer in the way of medicine.

Often, nurses find themselves in the traditional female role of being in the middle. We are the bridges between physicians and patients, explaining to each what the other is trying to communicate. We facilitate interactions between patients and family members, between parents and lovers, between administrators and their peers. In nursing schools, we are trained to

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advocate for our patients, sticking up for them when they are unable to do it for themselves. We try to represent them, encourage and empower them to make decisions that are informed. Frequently, we find ourselves at odds with physicians who see us as underlings, meddling in their "orders."

We are also the keepers of secrets; secrets from family members, from physicians, and even from county coroners. When confronted by a patient determined to end a life that has become severely limited and painful, many physicians simply will not intervene. More often than not, it is the nurse who finds the patient dead, or who becomes the confidant of the patient's suicide plan. A nurse's license to practice, not to mention her personal ethics, can be jeopardized.

Nursing people with AIDS is about mortality. The nearness to dying and loss, the mystery of the last heartbeat between life and death attracts us. We prepare patients as best we can for the transition, and we wait. Bearing witness to the very powerful moment of death and sharing those mysteries keeps many of us working in this field. It is an honor and a privilege not lost on AIDS nurses.

This work has brought about exponential personal growth. We have been challenged by patients who ask, "Am I dying now?" or by mothers taking their sons or daughters home to die who want to know "What will it be like? What will happen?" and "Will it hurt?" We have tried to answer these questions to soothe loved ones and comfort our patients, and to deal with the inevitable questions of our own living and dying. Some of us have felt a new appreciation for life. Some of us have started doing things we were always afraid to do—taking risks in case we, too, run out of time.

Many nurses identify with patients who have been oppressed and, conversely, have difficulties with patients with whom they do not identify. Patients with long histories of psychiatric illness or addictions or who have been otherwise marginalized or abused since childhood challenge us to care and to learn different ways of giving. One must trust in order to feel cared about. Learning to approach someone who has not had a single positive experience with social institutions works our hearts and our nerves. We were humbled by one of our patients who said it so well: "Remember, anger is really fear in drag."

As intimate caregivers, we develop intense relationships with our patients and with each other. We enjoy the feeling of these relationships; they are described by words like *primal*. We are attracted to the passion, the drama, the humor, and the opportunity of human experience. We are present for the transactions in abusive family and partner relationships, as well as complete unconditional love between people. We have seen our patients' loved ones rise to the occasion and provide exhaustive care, and we have seen them sink to abandonment and regret. It is a rich environment of human experience, behavior, lifestyle, and culture.

AIDS brings a certain continuity between providers and patients. Many of

us have known our patients over a period of years, from diagnosis to death. Patients confide in us, bring us to their most essential private places, and talk about the deeply felt issues of the human soul. We value these long-term relationships and know that they are therapeutic for both patient and caregiver.

The relationships that nurses develop with each other can be equally profound. It is necessary to bond and to trust in order to accomplish our jobs and support one another to go through these experiences. For most of us, the only people in our lives who understand or relate to what we do are other nurses. Our families can tolerate only a little of the story, but get a group of nurses together and the storytelling can go on late into the night . . . with great detail and considerable delight.

We are frequently asked how we live with burnout and continue doing this work for many years. Supportive work environments and individuals who are self-aware and know how to take care of themselves are key. We don't find the work inherently depressing. It is sad and stressful, challenging both personally and politically, but we agree that we get more out of it than we could ever put into it.

Last year, 1993, marked the ten-year anniversary of the opening of the HIV/AIDS program at San Francisco General Hospital. For many, it was also a personal tenth anniversary working with people with AIDS. It gives us pause to consider this fact. Early in the epidemic, some nurses were convinced (even hopeful) that they would be out of work in a few years, that a cure would be found. Passing this ten-year mark, and the ten thousandth death in San Francisco (which has a total population of less than 700,000) is an event with significant implications for our well-being as health care workers. We, too, have lost lovers, friends, and coworkers. HIV/AIDS crosses all the traditional protective boundaries of professional caregivers, as the professional distance gives way.

## CONCLUSION

Looking into the future, it's impossible to imagine the historic global impact that the AIDS epidemic will have had when it runs its course. Already it has had a transforming effect on the health care system and on the role of nurses in particular. When we try to project what this next decade will look like, we have to take into account the context and impact of health care reform. We are in the beginning stages of massive changes whose outcomes are unpredictable. How responsive will health care institutions be to the needs of patients/consumers under "managed competition"? How would nursing as a profession fare under a system of universal access? Over the past ten years, the payers of medical bills (insurance companies, HMOs, and the government) have increasingly determined standards of care. They are making health care decisions together with their physician-consultants. Nurses,

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patients, and in many cases primary care providers, are not at the decision-making table. The realities of the bedside are thus absent when critical decisions are being made.

If nurses' depth of knowledge and expertise are to be counted, we need to become literate in the economics of health and claim a place in the national debate for health care reform. Armed with a growing sense of empowerment, having proven ourselves again in the AIDS epidemic (and in every other field of health care), we have a far-reaching perspective that, in its better moments, can advocate, articulate, pressure, and produce the quality health care that is the right of every individual in society.

Our experience on the front lines gives us the ability to discern what the points of effectiveness and efficiency are. In the absence of a cure for AIDS, effective and efficient care means acceptance of and respect for the individual regardless of transmission category or health insurance coverage. It means commitment to providing comfort and care, to relieve pain and suffering, and to assist the dying.

So what is our message? It is simply that we value our work, our patients, and our contribution. The spiritual aspects of our job, the social activism, the connections with human souls in need, and the opportunity to practice exquisite caring are all part of the payback we receive.

It is an honor to share this struggle with the thousands of people with HIV/AIDS we have known.

## NOTE

<sup>1</sup>See James H. Jones, *Bad Blood: The Tuskegee Syphilis Experiment*. New York: The Free Press, 1993.

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